NUTRITIONAL CARE IN ADVANCED CANCER: THE EXPERIENCES OF PATIENTS, FAMILIES, AND HEALTH CARE PROVIDERS

By

Susan Elaine McClement

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of

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ABSTRACT

Anorexia and cachexia are prevalent problems in palliative cancer patients. To date, however, the majority of research related to these issues has been biomedical in nature. While this line of inquiry has produced important information regarding the pathophysiology and clinical management of cancer malnutrition, little is known about the experience of nutritional care from the perspective of patients, families, and health care providers. The minimal literature that exists on this topic suggests that these key stakeholders may hold divergent views about what constitutes appropriate nutritional care in the face of advanced disease, and that this divergence results in conflict among and between these parties. However, the concepts relevant to this dynamic are poorly understood and conceptually underdeveloped. Therefore, the grounded theory approach to data collection and analysis was used to develop a beginning substantive theory aimed at uncovering the social processes inherent in patient, family and health care provider interaction around the issue of nutritional care.

Data were collected, by means of the conversational interview, participant observation, and chart review, from 13 cancer patients receiving in-hospital palliative care, 13 family members, 11 health care providers delivering in-hospital palliative care, and 10 bereaved family members. The basic psychosocial problem uncovered in the data was family members' needs to balance the means and goals of nutritional care while simultaneously meeting their own needs and goals related to the provision of this care. The unifying theme of "doing what's best" integrated the major categories into the key analytic model in this study. "Doing what's" best represents a continuum of behaviors and strategies, and includes the sub-processes of "fighting back: it's best to eat" ; "pseudo-surrendering: holding on while letting go"; and "letting nature take its course: it's best not to eat." The extent to which family members embrace a particular sub-process and/or might move back and forth among them is a complex process involving many factors related to the patient, family member, health care provider, and the context in which the interaction about nutritional care takes place.

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CHAPTER ONE:

INTRODUCTION

This purpose of this introductory chapter is to: i) outline the purpose of the study; ii) provide rationale supporting the need for the study; ii) identify the research questions addressed in the study; iii) articulate the assumptions underpinning the research and; iv) provide definitions of the concepts related to nutritional care in advanced cancer as they appear in the empirical and practice-based literature.

Statement of the Problem

Anorexia, weight loss, and malnutrition are prevalent symptoms in individuals with terminal cancer (Bruera & Neumann, 1998). It is estimated that these physically and emotionally devastating problems occur in upwards of eighty per cent of this patient population prior to death (Walker & Bruera, 1998). Anorexia and weight loss are reported to be salient cues of disease progression for both family members and health care providers. For families, these symptoms are seen as a certain sign of impending death and constitute a source of considerable anxiety (MacDonald, Alexander, & Bruera, 1995). As a result, family members frequently expend much energy in preparing food, and encouraging the individual with cancer to eat. When these efforts fail family members become increasingly frustrated, angry, and distressed (Holden, 1991).

For clinicians, the presence of anorexia and weight loss in cancer patients serve as poor prognostic indicators (Costa, Lane, Vincent, & Siebold, 1980; Lindsey, Piper, & Stotts, 1982). The clinical consequences of malnutrition have been widely reported in the literature and include a reduced response to anti-neoplastic drugs, decreased tolerance to radiation and chemotherapy (DeWys, Begg, & Lavin, 1980), increased rates of perioperative complications (Smale, Mullen, Buzby & Rosato, 1981), poor performance status (Bozzetti, Amadori, & Bruera, et al. 1996), increased symptom distress, and decreased survival (Bruera & MacDonald, 1988). These findings have prompted researchers to try and identify pharmacological and nutritional interventions to manage the problem of cancer related malnutrition. Unfortunately, the empirical literature documents that aggressive oral, enteral, and parenteral nutritional do not circumvent weight loss in advanced cancer patients, increase survival (DeWys, Begg, & Lavin, 1980; Nixon, Moffit, & Lawson & Ansley, 1981; Shamberger, Brennan, Goodgame et al., 1984) or improve quality of life (Bruera & Fainsinger, 1995; Koretz, 1984). Therefore, the identification of nutritional interventions resulting in improved life expectancy and quality of life for terminal cancer patients have yet to be realized.

There is some evidence in the literature to suggest that terminally ill cancer patients tend to be less concerned about their lack of appetite, than about symptoms such as pain, breathing difficulties, and weakness (Holden, 1991). Moreover, qualitative interviews with terminally ill anorexic cancer patients suggest that they would prefer family members be less concerned about their nutritional intake (Holden, 1991). Unrelenting attempts to get the patient to "eat something" have been reported as a source of conflict between terminally ill cancer patients and their family caregivers in the palliative care literature (Holden, 1991). Palliative care clinicians concur that "family members can sometimes make mealtimes a battle ground when they strenuously force food, all with the best intentions, on their anorexic family member (Walker & Bruera, 1998, p.7)."

Issues related to nutritional care may also be a source of conflict between family members and health care providers. Health care providers working with palliative cancer patients are limited in the scope of interventions they can readily offer in response to the problem of malnutrition and wasting. Clinicians may thus direct their energies toward the management of symptoms that are more responsive to amelioration. However, the direction of minimal attention to nutritional issues by health care providers may be misunderstood by family members of advanced cancer patients. Atwood (1978) suggested that when an individual is admitted to a hospital setting, family members expect health care providers to attend both to the professional care needs that prompted admission, and the needs that the family attended to at home, such as nutrition. When health care providers engage in what Atwood (1978) has termed the "selective neglect" of certain care behaviors, conflict between health care providers and family members may ensue.

Patients, families, and health care providers are collectively involved in issues related to managing nutritional care in advanced illness. Patients directly experience the symptoms of anorexia and cachexia, and are the recipients of the care designed to palliate these symptoms. Family members witness the physical deterioration and symptom distress of the patient and suffer vicariously in the process (Turner, 1992; Kristjanson, 1986; Kristjanson, 1989a). They also observe the actions of health care providers in response to the occurrence of anorexia and weight loss. In so doing, families receive and evaluate the patient's care in terms of their expectations and perceptions about that care

(Kristjanson, 1991; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Health care providers are charged with the responsibility of assessing the patient's status and charting the most appropriate course of action. However, their planned interventions related to nutritional care may be at odds with the treatment decisions deemed optimal by family members. That is, incongruence may exist between health care providers and family members with respect to what constitutes appropriate nutritional care in the palliative care context.

These differences in perception may result in conflict between the patient, family, and health care provider triad, and family member dissatisfaction with care. Unresolved issues about nutritional care may result in food becoming a focal point for the family, and as such, have the potential to interfere with important grief work for family members (Gallagher-Allred, 1988; Kemp, 1999). This potential sequella is troublesome, given that unsatisfactory care experiences have been linked to the deterioration of health in family members of palliative cancer patients (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996).

Despite the apparent pervasiveness of this emotionally charged and often conflict-laden aspect of palliative care, the experience of nutritional care from the perspective of patients, families and health care providers is not well understood. Much of the research attention related to nutritional issues in palliative care has focused on delineating the mechanisms of cachexia, pharmacological treatment of anorexia and chronic nausea, and evaluating the effects of oral, enteral and parenteral nutrition. While these lines of biomedical inquiry have produced important information related to the pathophysiology and treatment of cancer anorexia-cachexia, they are but one pathway to knowledge about this issue (McClement & Woodgate, 1997). People's interpretations of a situation are influenced by their social interactions with others and the socio-cultural environment in which they exist (Kleinman, 1988). An alternative to the biomedical model of inquiry is required if the area of nutritional care in advanced cancer is to be fully understood. A research approach that contextualized the highly personal nature of the nutritional care experience, emphasized intentionality and the conscious construction of meaning, and acknowledged the socio-cultural dimensions in which these experiences are embedded appeared warranted; hence the need for this study.

Research Questions

Grounded theory methodology was used to examine the issue of nutritional care in the palliative cancer context. Rationale for selection of this particular approach, and a more thorough discussion of the grounded theory method is presented in Chapter Three. The type of methodology used for the study is necessarily introduced at this point, because the method bore directly on the initial type of research question asked, and the way in which it evolved over time.

The aim of using the grounded theory method is to develop theory (Stern, 1980). An inherent assumption in using the grounded theory approach to study a phenomenon is that the concepts relevant to the phenomenon are either poorly understood, conceptually underdeveloped, or have yet to be identified (Strauss & Corbin, 1990). The question or series of questions posed by the researcher therefore must provide both the flexibility and freedom to explore a phenomenon in depth (Strauss & Corbin, 1990).

The nature of grounded theory methodology challenges the researcher to start with a research question that is at once neither too broad nor too narrow in its exploration of a phenomenon, while being oriented toward action and process (Creswell, 1994). Research questions are subsequently honed and refined as data is generated and analyzed. Wilson (1989) contended that it is impossible to ask a "truly accurate" research question before beginning any grounded theory study. Thus the purpose of the original question posed by the researcher at the outset of the investigation merely lends focus to the study (Streubert & Carpenter, 1999). For example, in this particular study, the grounded theory question asked at the time of the student's proposal defense had to do with examining the meanings that cancer patients, family members, and health care providers ascribed to their experiences with nutritional care in the terminal phase of illness. This original question identified the phenomenon to be studied (i.e. nutritional care in the context of terminal cancer), and identified the perspectives from which the phenomenon would be investigated. Moreover given that the constituted meanings of patients, families, and health care providers are expressed through symbols and social interaction, the question was also oriented toward process and action.

During the course of field work it became readily apparent that much of the action and social interaction of patients and health care providers as it relates to nutritional care in the palliative care setting was predicated on the behavior of family members. The initial query was thus supplanted with the following more specific and refined question: How do families of palliative cancer patients balance the means and goals of nutritional care while meeting their own needs related to the provision of nutritional care?

Assumptions Underlying the Study

The following assumptions underpin this study.

1. There are cancer patients in the terminal phase of illness for whom nutritional support becomes increasingly inappropriate.

2. Family members are co-participants in the cancer patient's illness experience (Kristjanson, 1986).

3. Family members are able to articulate their perceptions and concerns regarding the palliative care their relative receives (Kristjanson, 1986; 1989a; 1989b).

4. Patients are able to articulate their perceptions and concerns regarding the palliative care they receive (Groebe, Ahmann, & Ilstrup, 1982).

5. Health care providers are able to articulate their perceptions and concerns regarding the palliative care they deliver to patients and families (Vachon, 1995).

6. Patients, families, and health care providers may hold divergent views about the role of nutrition in advanced cancer care.

7. Cancer related anorexia and cachexia are often more problematic for the family than the individual with advanced disease (Gallagher-Allred, 1995).

8. Food and eating have strong symbolic connections with survival (Holden, 1991).

9. Eating is a highly socialized process with great cultural and ethnic variances (Donovan & Pierce, 1976).

10. The significance of food in health and illness is culturally mediated (Murcott, 1983).

11. The preparation and serving of food expresses love and caring, and caregivers derive comfort form performing these functions (Benoliel, 1978).

12. The inability of patients and families, to engage in long standing rituals related to food signifies the loss of significant roles and role relationships (Benoliel, 1978).

13. There is a widespread intuitive assumption that the physical and emotional well being of terminally ill individuals is enhanced by the provision of artificial nutrition and hydration (McCann, Hall, & Groth-Juncker, 1994).

Definition of Terms

The following terms related to the area of nutritional care in advanced cancer patients are referred to frequently throughout the following chapters, and are thus presented here in order that the reader may become familiar with them. Their definitions are provided below. Note that the terms defined here do not include the operational definitions of concepts that emerged following data analysis. Those definitions are included in Chapters Five through Nine of this dissertation wherein the findings of the study are discussed.

Advanced cancer: also referred to as terminal cancer. In Stage III advanced cancer, clinical examination reveals an extensive primary tumor (i.e. fixation to deeper structures, bone invasion, and regional lymph nodes). The lesion may be operable, but not amenable to complete resection. Gross residual disease is left behind. Stage IV cancer is characterized by distant metastasis beyond the primary tumor site. The malignant lesion is inoperable and there is little or no chance for 5-year survival (i.e. less that 5%) (Griffith, Murray, & Runo, 1984).

Anorexia: diminished appetite; aversion to food (Pugh, 2000, p. 92).

Cachexia: a profound state of ill health and poor nutrition with body mass wasting (Lum & Gallagher-Allred, 1984).

Cancer-anorexia-cachexia-syndrome (CACS): a systemic response to cancer manifested by malnutrition, weight loss, and muscular weakness. The basis of the anorexia is believed to be a multi-factorial metabolic disturbance that contributes to the development of cachectic wasting, which in turn reinforces the anorexia by the release from the tumor of an anorexigenic humoral product that stimulates the satiety center in the hypothalamus, producing appetite loss (Alexander & Norton, 1995; Bruera & Higginson, 1996).

Enteral feeding: gastrostomy or jejunostomy routes that bypass dysfunctional parts of the gut by using a thin flexible tube to deliver nutrients to functional parts (Pugh, 2000, p. 597).

Intravenous (IV) therapy: the infusion or administration of fluids through a vein. This method of fluid replacement is used most often when a patient is suffering from severe fluid deficit and is unable to drink fluids because he is unconscious, recovering from surgery, unable to swallow normally, vomiting persistently or losing large amounts of fluid through other means (Brunner & Suddarth, 1986).

Nutritional care: refers to the food and liquid requirements of human beings for normal physiologic function (Pugh, 2000, p. 1245).

Palliative care: the active total care of patients whose disease is not responsive to curative treatment. It includes the management of individuals with progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life (Conill, Verger, Henriquez et al., 1997). A philosophy of care that is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, cultural and religious values, beliefs and practices. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team. (Victoria Hospice Society, 1998; Canadian Palliative Care Association, 1995).

Terminal phase of illness: the phase of the illness during which the patient experiences progressive physical deterioration and decline. Treatment is palliative rather than curative in nature (Benoliel, 1978; Lewandowski & Jones, 1988).

Total parenteral nutrition (TPN): refers to the provision of all nutrients to sustain life intravenously without using the intestinal tract (Silberman, 1989). Nutritionally adequate hypertonic solution is administered through an indwelling catheter into the superior vena cava. Also referred to as TPN , hyperailementation, intravenous nutrition, and intravenous alimentation (Brennan, 1981).

Summary

This chapter has provided an introduction to the study that was undertaken. Information was presented outlining the purpose and relevance of the study. The research questions driving the study and the assumptions underpinning it were identified. Definitions were provided of the concepts related to nutritional care in advanced cancer as they appear in the empirical and practice-based literature. The following chapter will examine the uses of literature in grounded theory research, and provide a review of literature relevant to the research project.

CHAPTER TWO:

Review of the Literature

Introduction

This chapter will provide an overview of the literature related to the study. It is important to note at this juncture that the uses of literature in a grounded theory study differ from the ways that literature is used in quantitative research. Therefore, a discussion of the uses of literature in grounded theory research prefaces the actual literature review.

The Use of Literature in Grounded Theory Research

The purpose of grounded theory research dictates the way that literature is used throughout the study. In quantitative research, the investigator examines the literature thoroughly "up front" and uses it to do such things as identify previous research in the area, identify knowledge gaps, operationalize study variables, examine methodological and instrumentation issues, and gain information that informs design and sampling decisions (Catanzaro, 1988). The literature is thus used from the outset of the project in an attempt by the researcher to gain what Wilson (1989) has termed a "scholarly frame."

In the course of discovering grounded theory, the researcher uses literature for different purposes over the course of the study (Chenitz & Swanson, 1986). However, unlike quantitative researchers, grounded theorists *ideally* collect data in the field prior to any extensive review of the literature. This deliberate step is done in order to prevent the researcher from prematurely adopting codes and categories from existing literature and applying them to the data, as opposed to generating one's own ideas. Given that the grounded theorist aims to "discover relevant categories and the relationships among them, and put together categories in new, rather than standard ways" (Strauss & Corbin, 1990, p. 49), their approach to literature is, of necessity, somewhat cautious and skeptical (Chenitz, 1986). This cautious scepticism is particularly important at the outset of the study. Too heavy a reliance on codes and categories "learned from the literature", as opposed to those generated by the analyst effectively closes off analysis and subsequent theory development (Glaser, 1978). Thus, consistent with the methodological assumptions of qualitative research, the literature is used in an inductive fashion so that it does not drive the questions being asked by the investigator.

Although a thorough review of the literature ideally is not conducted at the outset of a grounded theory project, researchers charged with the responsibility of writing proposals for academic settings and funding bodies are required to demonstrate an in-depth knowledge of the subject in order to have a competitive proposal. The issue becomes one of pragmatics for the researcher. As Chenitz (1986) noted, "if a full proposal is to be written, a complete review of the literature is conducted." (p. 45). This in-depth exposure to the literature requires that researchers be particularly vigilant about not latching onto ideas or concepts in the literature in the course of their analysis. Such vigilance is vitally important if the theoretical sensitivity, that is, the "personal quality of the researcher that facilitates an awareness of the subtleties of meaning of the data" (Strauss & Corbin, 1990, p. 41) and originality of the work are to be preserved (Wilson, 1989).

The analyst returns to the literature during the emergence of the major analytic scheme in the study. The purposes of the literature review at this point of the study are to to verify and elaborate categories in the model, and to learn more about intervening factors that have arisen. To that end, the literature review can be seen as an ongoing process that the researcher conducts in order to fulfill the needs of the analysis (Chenitz, 1986). At the end of the study, the grounded theorist again returns to the literature in order to see if and how their work fits with existing research, and to discern if their findings have contributed to the understanding of the phenomena under examination. It is at this point that the researcher is thoroughly familiar with the literature (i.e. has a scholarly frame), and can place his or her findings in context with existing empirical and theoretical work (Chenitz, 1986).

Literature Review

Consistent with the uses of literature in a grounded theory study, the literature presented in this section was reviewed with the aim of identifying past research in the area, and establishing a background to the project. An exhaustive literature review of all possibly related concepts and relationships salient to nutritional care was not conducted in advance, as such concepts and relationships needed to be allowed to emerge from the data. Literature that corresponded to the emerging theory and helped to integrate the study's findings is presented in Chapter Ten.

Current knowledge related to this study included five categories of literature: (1) malnutrition in advanced cancer; (2) clinical management of cancer anorexia and cachexia; (3) patient perceptions regarding declining nutritional intake; (4) family perceptions regarding declining nutritional intake; and (5) health care provider perceptions regarding declining nutritional intake.

(1) Malnutrition in Advanced Cancer

Malnutrition is a prevalent problem in individuals with cancer, occurring in upward of 80 per cent of individuals with this disease (Conill, Verger, Henriquez, et al., 1997; Walker & Bruera, 1998). Multiple factors contribute to the development of malnutrition and weight loss in cancer patients including treatment-induced toxicities, gastrointestinal obstruction, and malabsorption (Ottery, 1994). Decreased intake may also be secondary to uncontrolled pain, the side-effects of opioid medications, alterations in taste (Lesko, 1989; Lum & Gallagher-Allred, 1984; Walker & Bruera, 1998), the development of food aversions (Bernstein, 1985), and such psychological causes as anxiety and depression (Holland, Roland, & Plumb, 1977). However, the commonest form of malnutrition in this patient population is the cancer anorexia-cachexia-syndrome (CACS) (Walker & Bruera, 1998).

CACS is characterized by a constellation of symptoms, including anorexia, chronic nausea, asthenia, weight loss, changes in taste, and alterations in protein, carbohydrate, fat, and energy metabolism (Alexander & Norton, 1995; DeWys et al., 1980; Nelson, Walsh & Sheehan, 1994; Theologides, 1986; Vigano, Watanabe, & Bruera, 1994). CACS occurs most frequently in individuals with lung and gastro-intestinal, and myelodysplastic syndromes, and is less common in those with breast cancer until the disease is far advanced (MacDonald, Alexander & Bruera, 1995).

While individuals with advanced cancer frequently suffer from decreased oral intake, the anorexia and cachexia seen in CACS do not result solely from this cause. The once widely contended belief that the extreme metabolic demands of the tumor "steals calories" from the host, thereby inducing cachexia, no longer holds (Vigano, Watanabe, & Bruera, 1994). Research now suggests that tumors interact with the immune system producing multiple metabolic abnormalities that lead to anorexia, protein loss, and lipolysis, with resultant malnutrition (Walker & Bruera, 1998). Specifically, it is believed that the release of cytokines such as tumor necrosis factor (tnf), interleukin-1-6, and interferon gamma from tumor cells may initiate the cancer anorexia-cachexia syndrome (Alexander & Norton, 1995; Bendtzen, 1988). Viewed within the current model of CACS, anorexia is associated with the onset of metabolic abnormalities and is now thought to be the *result,* as opposed to the primary *cause*, of cancer cachexia (MacDonald, Alexander, & Bruera, 1995).

(2) Clinical Management of Cancer Anorexia-Cachexia

(a) Nutritional Intervention: Total Parenteral Nutrition: The extreme weight loss and cachexia seen in individuals with terminal cancer is viewed by clinicians as a poor prognostic indicator (Costa et al., 1980). Individuals with CACS have poor performance status, decreased tolerance to radiation and chemotherapy, and increased surgical complications in the postoperative period (Bruera & Fainsinger, 1995). The enormous impact of malnutrition for individuals with cancer has prompted many researchers to try and reverse CACS with aggressive nutritional support, notably total parenteral nutrition (TPN), and enteral nutrition (EN). Indeed, more than two decades ago, it was declared that the use of TPN as an adjunctive therapy would significantly reduce morbidity and mortality in patients with malignant disease (Dudrick & Ruberg, 1971). While the results of some studies initially supported this assertion, improvements in life expectancy have not been borne out in randomized controlled trials (Burt, Gorschboth, & Brennan, 1982; DeWys et al., 1980; Nixon, Moffit, Lawson, & Ansley, 1981; Shamberger, Brennan, Goodgame, et al., 1984).

Koretz (1984) reviewed 16 prospective, randomized, controlled trials evaluating the impact of TPN in oncological situations. TPN was not shown to significantly improve survival in cancer patients receiving radiation or chemotherapy (Koretz, 1984). Moreover, a study conducted by Nixon and colleagues (1983) concluded that cancer patients receiving TPN demonstrated statistically significant reduced survival compared to controls ($p<0.05$). However, the findings from this study must be interpreted with caution as the control group had fewer metastatic sites than the group receiving TPN.

There is agreement in the literature that malnourished cancer patients have increased rates of infection and complications following surgery (Smale, Mullen, Buzby, & Rosato, 1981). However, there is lack of consensus among researchers with respect to the effects of nutritional therapy on the incidence of surgical complications. Smale and colleagues' (1981) retrospective, non-randomized review of 159 patients undergoing major abdominal, thoracic or head and neck surgery concluded that the provision of at least six days preoperative TPN was associated with significantly reduced morbidity and morality ($P<0.001$).

The efficacy of peri-operative TPN in reducing operative morbidity and mortality has also been documented in randomized prospective studies. Williams and associates (1976) reported significantly fewer wound infections in patients undergoing surgery for gastric carcinoma who were given 7-10 days of pre-operative TPN as compared to normally fed controls. There were no statistically significant differences between TPN treated patients and controls with respect to other post-operative complications.

Muller and colleagues' (1982) examination of the effect of 10 days of pre-operative TPN on the post-operative complication rates of patients with gastrointestinal tumors concluded that major complications and mortality rates were significantly lower ($p<0.05$) in patients given TPN groups versus orally fed controls. In contrast, other studies have suggested that preoperative nutrition does not reduce postoperative complications and mortality. In a randomized, controlled study investigating the effect of TPN on 26 patients undergoing surgery for gastrointestinal malignancies, Holter and associates (1976) reported no difference in the postoperative complication rate between patients randomized to receive TPN 48 hours preoperatively and 10 days after surgery, and non-TPN controls. However, given that all patients had experienced a greater than a 10 pound pre-operative weight loss, it could be argued that 48 hours of preoperative TPN was inadequate to reverse the catabolic state of these patients.

In order to resolve the uncertainty resulting from the conflicting results shown in previous clinical trials, Detsky and colleagues (1987) conducted a meta-analysis to evaluate the effectiveness of peri-operative parenteral nutrition. Meta-analysis is a statistical method that attempts to achieve consensus from the result of numerous small trials that have each attempted to address a closely related clinical question (Miliakkal, Blackburn, Willcuts et al., 1992). Destky's (1987) examination of 18 controlled trials demonstrated that there were no significant differences in the incidence of complications and morality rates between patients who received preoperative nutrition, and those who did not.

The ability of the trials selected for the meta-analysis to provide conclusive results may have been limited by methodological flaws. Thirteen out of 17 studies reviewed failed to exclude patients who were not malnourished from the trial. Moreover, strict criteria for assessing surgical complications were not clearly articulated, and individuals assessing clinical outcomes were not blinded to the treatment given (Detsky, Baker, O'Rourke, & Goel, 1987).

In summary, the effects of TPN on the incidence of surgical complications are debatable. While there is some evidence in the literature to suggest that a course of preoperative TPN can reduce postoperative complications and mortality (Muller et al., 1982), the meta-analysis conducted by Detskey and colleagues (1987) concluded that there were no significant differences in the incidence of complications and mortality between cancer patients who received preoperative TPN and orally fed controls.

Because the majority of palliative cancer patients have metabolic changes that do not respond significantly to aggressive nutritional support (Bruera & Fainsinger, 1995; Bruera & MacDonald, 1988; Vigano, Watanabe, & Bruera, 1994), the routine use of parenteral nutrition in this patient population is deemed to be inappropriate. However, the literature suggests there may be a sub-group of advanced cancer patients suffering from obstructive cachexia who may benefit from artificial nutritional support (MacDonald, Alexander & Bruera, 1995). These include individuals suffering from head and neck tumors with upper digestive tract obstruction, and those with ovarian cancer with intermittent small-bowel obstruction (Herber, Byerely, Chi, et al., 1986; MacDonald). To date however, this hypothesized benefit has not been empirically tested.

b) Nutritional Intervention: Oral Nutrition: Given that parenteral nutritional support has not been shown to circumvent cancer cachexia, the most reasonable approach for dealing with malnourished palliative cancer patients is to allow them an ad libitum diet (Vigano, Watanabe, & Bruera, 1994). This strategy is consonant with Holden's (1991) finding from qualitative interviews with anorexic palliative cancer patients (n=10) that they would prefer to control the amount and nature of food served to them. Moreover, the literature suggests that aggressive oral feeding is of limited value because improvements in daily caloric intake have not been shown to be sustainable over time. In a prospective study conducted by Bruera and colleagues (1988), nutritional counseling improved the daily oral caloric intake in a series of 50 patients by an average of 450 calories per day. Unfortunately, this improvement was maintained for less than a month.

The wisdom of aggressive oral feeding must also be examined in relation to chronic nausea–a troublesome symptom experienced in upwards of 68% of patients with advanced cancer (Bruera & Fainsinger, 1995). While there are multiple causes of chronic nausea in the advanced cancer population, nausea caused by gastroparesis as a result of autonomic failure is highly implicated in the presence of malnutrition. (Bruera, Catz, Hooper, Lentle, & MacDonald, 1987; Bruera, Chadwick, MacDonald, Fox, & Hanson, 1986; Bruera & Fainsinger, 1995). A study conducted by Bruera and colleagues examining the incidence of autonomic failure in 43 patients with advanced breast cancer and 20 normal sex and age-matched controls demonstrated a significantly marked delay in gastric emptying times in the patient group versus controls ($p<0.001$). This suggests that aggressive oral feeding has the potential to greatly exacerbate chronic nausea.

c) Pharmacological Management of Cancer Anorexia and Cachexia: Given the lack of efficacy of enteral and parenteral nutrition in reversing cancer anorexia and cachexia, increased research attention has been directed toward the identification of pharmacological therapy to treat these symptoms. The main pharmacological approaches used in the management of cancer anorexia include the use of corticosteroids, progestational drugs, cyproheptadine, hydrazine sulphate, and cannabinoids (Bruera & Fainsinger, 1995).

Corticosteroids are used to treat a wide variety of symptoms seen in advanced cancer patients (Ettinger & Portenoy, 1988; Far, 1990). One of the results of steroid therapy is increased sense of well being. Therefore, researchers have hypothesized that treatment with corticosteroids may alleviate the symptoms of anorexia and weakness. While preliminary findings were initially promising, the beneficial effects of steroids appear to short lived in the palliative cancer population.

In a randomized trial conducted by Moertel and colleagues (1974), patients with advanced gastrointestinal cancer (n=116) who received the corticosteroid dexamethasone demonstrated significant improvement in appetite and strength compared to controls receiving placebo. These improvements were only maintained for four weeks however, and no significant increases in weight grain or survival occurred.

Bruera and colleagues (1985) conducted a 14-day, randomized, double-blind crossover trial comparing the oral glucocorticoid, methylprednisolone against placebo for the relief of pain and other symptoms in 40 terminally ill cancer patients. Seventy-seven per cent of patients (24/31) demonstrated an increase in appetite and daily activity, while 71% experienced a decrease in pain intensity and amount of analgesia required.

Increased research attention regarding the use of progestational drugs to treat anorexia and cachexia in terminal cancer patients arose from the findings of studies conducted in the late 1980's which demonstrated significant weight gain in patients with hormone-responsive tumors (Tchekmedyian, Tait, Moody, Greco & Aisner, 1987). Randomized, double-blind, placebo-controlled trials conducted in both American (Feliu, Gonzales-Baron, & Berrocal, 1992; Loprinzi, Ellison & Schaid, 1990; Tchekmedyian et al., 1990) and Canadian centres (Bruera, MacMillan, Hanson, Kuehn, & MacDonald, 1990) have provided evidence of appetite stimulation, increased food intake, and substantial weight gain that was not attributed soleley to fluid accumulation.

The anti-histiminic drug cyproheptadine has been demonstrated to have appetite-stimulating and weight enhancing effects in both patients with CACS and normal controls (Nobel, 1989). A randomized, placebo-controlled, double blind clinical trial conducted by Kardinal and colleagues (1990) demonstrated appetite stimulation and increased food intake in patients receiving cyproheptadine versus controls. However, the weight loss in patients receiving cyproheptadine continued unabated.

Some palliative care clinicians and researchers are demonstrating a renewed interest in the well known effect of weight gain secondary to the use of dronabinol in the management of anorexic, cachectic cancer patients, and patients with human immunodeficiency virus (HIV) wasting syndrome (Balog, Epstein, Amodio, & Groton, 1998; Beal et al., 1995). Dronabinol is a synthetic derivative of the major active substance in marijuana (Lilley & Aucker, 1999). Patients taking dronabinol typically experience increased appetite, and mood, and a decrease in the rate at which they lose weight (Wadleigh et al., 1990). However, escalating dosages of dronabinol are also associated with negative psychotomimetic effects in many patients, thereby limiting its effectiveness.

Perceptions Regarding Decreased Nutritional Intake

a) Patient perceptions: Minimal literature exists examining palliative cancer patients' perceptions regarding decreased intake. When they are examined at all, issues related to decreased patient intake tend to focus on the examination of symptoms that patients experience secondary to decreased intake of food and fluid.

Burge (1993) conducted a cross-sectional survey of inpatient palliative care subjects (n = 52) with minimal to no fluid intake. The aims of the research included a determination of the distribution and severity of symptoms thought to be associated with dehydration, and clarification of the severity of symptoms thought to be associated with dehydration in this patient population using objective measures of dehydration. Using 100 millimeter visual analog scales, patients rated their symptoms of pain, thirst, nausea, bad taste in the mouth, dry mouth, pleasure from drinking and fatigue. There was no association between the patient's level of thirst and amount of fluid intake. Paradoxically, as fluid intake increased in these patients, perceptions of thirst also increased. This finding challenges the assumption that provision of normal fluid volumes to the dying relieves the sensation of thirst.

Symptoms of hunger, thirst and dry mouth were also monitored by McCann and colleagues (1994) in a prospective evaluation of consecutively admitted terminally ill patients to a comfort care unit (n=32). These researchers reported that 62% of the sample either experienced no thirst, or were thirsty only at the time of their admission to hospital. Part of the confusion around issues of dehydration in conceptual in nature. For example in the McCann study, the terms thirst and dry mouth were used interchangeably. Thus, it is not possible to distinguish whether or not thirst was used to describe what in essence was the sensation of a dry mouth, or a combination of dry mouth and thirst secondary to dehydration. However, the findings do suggest that these symptoms were relieved with ice chips, oral care and sips of liquids. Moreover, the results of this study indicated despite an oral intake that was below 75% of daily requirements, only a minority of patients reported feelings of hunger and thirst. Clearly, the majority of patients did not report distress due to markedly diminished intake of food and fluid.

b) Family perceptions: There is some suggestion in the literature that the experience of watching a terminal cancer patient waste away is stressful for family members (Higginson & Winget, 1996; Stephany, 1991). However little empirical work has been published examining the ways in which family members actually do experience this event or ascribe meaning to it.

Only one study was located examining primary caregiver perceptions of declining intake in terminally ill patients. A phenomenological study conducted by Meares (1997) explored the meaning of nutrition cessation in adult in-home hospice patients with cancer as described by female primary caregivers (n=7). Meares (1997) characterized caregiver experiences as emotionally painful and replete with "ongoing and spiraling losses" (p. 1751). Caregivers in this study were portrayed as "vigilant sustainers" in their attempts to maintain normal intake of food and fluid in the face of the patient's physical deterioration. An interesting and intuitively contrary finding is that caregivers in Meares' (1997) sample did not equate intake cessation with suffering. Explanations for this finding are not entertained by the author.

Holden's (1991) qualitative study examining the emotional impact of cancer anorexia on the patient and family provides additional insight into caregiver perceptions and experiences associated with patients' declining intake of food and fluid. Semi-structured interviews were conducted with 14 patients and their primary caregivers to elicit data. The findings of the study revealed that: i) the amount of food and fluid consumed by the patient constituted a barometer or reading for the family of the patient's overall condition; ii) that the patient's loss of appetite constituted a major source of anxiety and conflict within the family unit; and that iii) the majority of patients viewed anorexia to be of less concern than other symptoms they were experiencing, and wished that family members would focus less energy on encouraging them to eat. (Holden, 1991). Holden (1991) also reported that female caregivers experienced greater anxiety than male caregivers, because of disruption of the customary roles of cook and nurturer with which females strongly identify.

Parkash and Burge (1997) have identified issues that are important to family caregivers when deciding whether or not artificial hydration should be provided to patients with advanced cancer. Semi-structured interviews were conducted with family caregivers (n=7) of patients enrolled in a palliative care program in eastern Canada. The findings from this qualitative study indicated that decision making regarding the use of hydration in terminal illness was influenced by such factors as family member perception regarding the symptoms associated with dehydration, ethical concerns, emotions, and information concerning artificial hydration. However, as Parkash and Burge noted, "most of those whom we interviewed had their experience shaped by caring for a family member at home, not in the hospital." (p. 26). The extent to which these issues might emerge in the hospital setting is unknown.

c) Health Care Provider Perceptions: The literature examining health care provider perceptions regarding decreased intake of food and fluid in terminal patients has largely focused on the perspectives of hospice nurses. There is consensus in this literature that these nurses do not perceive minimal intake or even intake cessation as causing discomfort in dying patients. In a 1989 survey of hospice nurses (n=96), Andrews and Levine (1989) found that approximately two-thirds of the respondents agreed with the statement, "Dying patients who are dehydrated rarely complain of thirst."

There is less consensus in the literature among physicians regarding the perceived benefits of intake cessation, as evidenced by physician perceptions regarding the use of IV therapy in terminal illness (Micetich, Steinecker, & Thomasma, 1983). These reports suggest that physicians have difficulty discontinuing IV therapy, even if patients have no hope of survival. The authors advance several reasons to explain this behavior. First, physicians may view IV therapy as "ordinary" means of treating the dying, and thus feel obligated to continue with such therapy. Second, reluctance to stop IV therapy may be due to fears of legal liability. Finally, not wanting to appear to abandon the patient, and feelings of guilt because there was nothing more they could offer the patient were factors also identified as potentially influencing physician behavior. Micetich and associates (1983) argued that the administration of IV fluids is sometimes contraindicated and should be forgone. However, the findings of their survey suggest that the provision of IV fluids to the terminally ill tends to be an automatic response for most physicians.

Summary

This chapter provided an overview of the uses of literature in a grounded theory study. The literature reviewed in this chapter relevant to the present study revealed that nutritional issues in palliative cancer care have been largely examined and understood from a bio-medical perspective. The minimal extant literature examining the thoughts, perceptions, and experiences about nutritional care in this context from the perspective of patients, families, and health care providers suggests that this nutritional care is a salient, and sometimes highly problematic area of care in the terminal phases of illness. This reality underscores the need for research to be conducted using a methodological approach that will allow for the examination of the social processes inherent in the interactions around nutritional care issues, in a setting where such interactions take place. The next chapter will provide an overview of the grounded theory method used to conduct the study.

CHAPTER THREE

THE GROUNDED THEORY METHOD

Introduction

The purpose of the following chapter is to describe the qualitative research method used in conducting the study, and to outline the procedures used in completing the research. The chapter begins with a brief overview of the grounded theory method, and the theoretical lens underpinning the method. The specific steps inherent in the grounded theory method are then described. The chapter concludes the researcher's rationale for selecting the grounded theory method to conduct the study.

The Grounded Theory Method: An Overview

Grounded theory is a qualitative research approach used to explore social processes inherent within human interactions (Baker, Wuest, & Stern, 1992; Streubert & Carpenter, 1999). American sociologists Barney Glaser and Anslem Strauss are credited with developing the grounded theory method in the 1960's when they first used this approach to examine the experience of dying patients (Glaser & Strauss, 1967). Through use of the grounded theory method, investigators seek to explore and describe phenomena in naturalistic settings, and uncover the practices, behaviors and beliefs of individuals or groups as they normally function in real life (Polit & Hungler, 1991). The grounded theory method involves the application of systematic steps and procedures that result in the development of an inductively derived theory that is "grounded in the data" (Strauss & Corbin, 1990). The theory that emerges provides theoretically complete explanations about a given phenomenon (Streubert & Carpenter, 1999).

The work of the grounded theorist is both inductive and deductive as opposed to being solely verificational in nature. Verificational, or theory testing research is linear in that the researcher identifies a problem, selects a theoretical framework, develops hypotheses, collects data, tests the hypotheses, and interprets the results. As such verificational research moves from a general theory to a specific situation (Polit & Hungler, 1991). In contrast grounded theory methodology combines both inductive and deductive research methods (Glaser & Strauss, 1967; Stern, 1980), in that the researcher engages in data collection and analysis simultaneously, and the concepts and propositions emerging from the data direct subsequent data collection.

Goetz and LeCompte (1984) asserted that the researcher's theoretical lens affects both the research questions that are asked, and the research strategies and approaches used in answering them. Because the grounded theory method is rooted in symbolic interactionism (Streubert & Carpenter, 1999), researchers using this method must examine social problems and the actions taken in response to these problems in light of social interaction, and the context within which interaction takes place. According to the theory of symbolic interactionism: 1) human beings act toward things on the basis of the meanings that the things have for them; 2) the meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows; and 3) meanings are handled and modified through an interpretive process by the person dealing with the things he or she encounters" (Blumer, 1969, p. 2). More simply stated, individuals are believed to behave and interact based on the ways they interpret, or give meaning to specific symbols in their lives. Symbols may constitute such things as objects, and both verbal and non-verbal expression. The meaning and value that people ascribe to particular symbols provides a means by which individuals interpret their world, and the other people who interact with them in that world (Stern, Allen, & Moxley, 1982).

Symbolic interactionism is an appropriate framework for use in this particular study because it: 1) emphasizes the importance of individual subjective perception of reality (LaRossa & Reitzes, 1993); and 2) postulates that meanings arise through a process of interaction with other people, and; 3) that meanings may be accepted, modified, or ignored in the context of a particular situation (Blumer, 1969). The experiences of cancer patients, family members, and health care providers regarding nutritional care in advanced cancer are rooted in their unique perceptions of, and experience with, this issue as well as their interactions with one another. As such, the use of a symbolic interactionism framework allows for the exploration of experiences in the context of the meaning nutritional care holds for these individuals in the patient's overall plan of advanced cancer care.

Sampling, Data Collection, and Analysis in the Grounded Theory Method

The processes of sampling, data collection, and analysis are intimately connected in grounded theory work. The following discussion will illustrate this interconnectedness.

Sampling procedures in grounded theory do not rest on the notion of representativeness. The sample in a grounded theory study, therefore, is not selected from the population according to certain variables prior to the study, as is the case in quantitative research (Polit & Hungler, 1991). Rather, sampling is directed by the goal of the types of coding procedures used by the analyst in examining the data. Data is usually generated through field observation and/or through the examination of documents. Field observation refers to the process whereby the researcher generates data through observation of the natural setting and the individuals in it, through interview, and audio or video-taping (Cormak & Llandaff, 1991). Data can also be generated through the recording of written field notes where the researcher records ideas, impressions, and reactions to events in the field.

As data is collected and generated through the processes identified above, researchers begin the act of coding the data. Coding occurs at three levels. In Level I or open coding, the aim of the researcher is to discover, name, and categorize phenomena (Strauss & Corbin, 1990). Level I codes are also referred to as substantive codes because they both codify the substantive content of the data and frequently use the words and expressions of participants themselves (Streubert & Carpenter, 1999). In the process of Level I coding, the analyst reviews the data that have been generated. Individual words and phrases within field notes and transcribed interviews that are believed to contribute to an understanding of "what is going on" in the data are then written in the margins of the document. Some data may be coded into more than one code. Though this will initially result in what feels like an unwieldy and "undifferentiated mass" (Strauss & Corbin, 1990), the coding of incidents and sentences into as many substantive codes as possible helps to ensure detailed theoretical coverage (Streubert & Carpenter, 1999). Because the aim of open coding is to discover, name, and categorize phenomenon, the aim of sampling at this stage of the study is to excavate as many potentially relevant categories as possible from the data (Strauss & Corbin, 1990). Of necessity, sampling procedures at this time includes sampling of individuals and situations that provide the researcher with the greatest chance or opportunity to collect relevant data about the phenomenon of interest in the study (Strauss & Corbin, 1990).

Some may object that such open sampling is rather indiscriminate. However, because the researcher does not know what concepts are theoretically relevant to the study at its outset, it is important to be "open to all possibilities". Thus, "openness as opposed to specificity, guides initial sampling choices" (Strauss & Corbin, 1990, p. 181).

In level II or axial coding, the data that was broken down and analyzed is "put back together in new ways", by the analyst by making connections between categories and sub-categories (Strauss & Corbin, 1990, p.96). The goal in axial coding is the delineation of a category and the conditions that give rise to it. This is accomplished through the use of a coding paradigm that denotes the context in which the category is embedded, the strategies by which it is managed, the intervening conditions influencing the strategies used, and the consequences of those strategies (Strauss & Corbin, 1990). The aim of axial coding is also to identify incidents that reflect differences and change in the coding paradigm, and to find as many differences as possible at the dimensional level in the data (Strauss & Corbin, 1990).

Given the aims of axial coding, the focus of sampling is on revealing and validating the relationships between categories and sub-categories, and to find evidence of variation and process within them. Thus axial coding requires that the researcher engage theoretical sampling, that is, "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p.176). Concepts are said to be theoretically relevant when they frequently appear in the data and achieve the status of categories. The specific sampling techniques used during axial coding are what Strauss and Corbin (1990) term relational and variational sampling. These types of sampling result in the researcher "tracking" categories and sampling different sites, subjects, and documents in order to find as many differences as possible in the data.

The final step in coding is referred to as Level III or selective coding. Selective coding is similar to axial coding, however it occurs at a higher level of abstraction. Selective coding refers to the process wherein the analyst: 1) selects the core category; 2) systematically relates it to other categories; 3) validates those relationships; and 4) fleshes out categories that need further development and refinement (Strauss & Corbin, 1990, p.116). Data analysis provides direction for new data collection that will help categories to become more fully developed and integrated. Because of the aims of selective coding, the sampling procedure at this point in the study becomes directed and deliberate (Strauss & Corbin, 1990), and is referred to as discriminate sampling. A researcher engaged in this type of sampling specifically samples persons, places, and documents with an aim to verifying relationships between categories and fill in categories that need further development (Strauss & Corbin, 1990).

While statistical sampling approaches demand that data collection must continue until a predetermined sample size is achieved (Wilson, 1989), in grounded theory, discriminate sampling proceeds until the point of saturation. Saturation refers to the state wherein no new or relevant data seem to emerge regarding a category, categories are well developed in terms of their properties and dimensions, and the relationships between categories are crystallized, and well established (Glaser & Strauss, 1967; Cormak & Llandaff, 1991). Therefore, the researcher using the grounded theory method samples until saturation is achieved.

There are two other fundamental characteristics of the grounded theory method that occur concurrently with sampling and data analysis. They are the constant comparative process and memo writing. Using the constant comparative method of analysis, the researcher compares incident with incident, and category with category in the data. The comparison of similar incidents enables the researcher to define the basic properties of categories, and the context under which the category exists. Each category is then compared with every other category to ensure that the categories are mutually exclusive (Streubert & Carpenter, 1999).

Memo writing requires that the researcher keep a permanent record of any hunches, thoughts, questions, and hypotheses during the course of the study. Memos are a tool designed to help the researcher examine and explore developing categories and the relationship between them. Thus, the process of memo writing in grounded theory research can be thought of as the means by which the analyst both records and facilitates the analytical process (Cormak & Llandaff, 1991).

Rationale for Using Grounded Theory for This Study

Grounded theory is but one of a myriad of methods available to investigators who wish to conduct qualitative research. How then, did grounded theory come to be chosen as the method of inquiry for this study? Stern (1980) asserted that there are two main uses for grounded theory. The first purpose of grounded theory is to generate theory where no theory exists. A second purpose for grounded theory is the construction of theory for familiar situations when existing theory is ineffective in resolving persistent problems. Given these uses, the grounded theory method was appropriate for this study. First, there is a paucity of research examining the socio-behavioral aspects of nutritional care in the setting of advanced cancer. The research literature is particularly devoid of the voices of patients and family members concerning this issue. Moreover, the social processes that exist within the provision of nutritional care to advanced cancer patients have not been delineated. These relatively unchartered waters underscore the need for theory development where no theory currently exists (LoBiondo-Wood & Haber, 1990).

Second, the literature that does address the issue of providing nutritional care to advanced cancer patients suggests that this aspect of care causes conflict between patients and family members, and family members and health care providers. Given that the goal and key to grounded theory is that it generates "theory that accounts for a pattern of behavior which is relevant and problematic for those involved' (Glaser, 1978, p. 93), the grounded theory approach is appropriate for this study. Moreover, the generation of a grounded theory has the potential to yield new insights on this problematic issue that may have implication for practice and education.

Summary

This chapter has provided an overview of the grounded theory method that was used to conduct the study. The theoretical perspective of symbolic interactionism and its relationship to grounded theory was presented. The interrelationship between the steps of sampling, data collection and analysis was outlined, and the steps inherent in each level of data analysis were described. The next chapter will detail the methods and procedures used in conducting the study.

CHAPTER FOUR:

METHODS AND PROCEDURES

Introduction

This chapter will detail the methods and procedures used to conduct the study. This includes a discussion regarding: a) the study setting; b) sampling, inclusion criteria, and recruitment; c) data collection and analysis; and d) ethical considerations. Measures used to enhance the scientific merit of the project are also presented.

Study Setting

The study was conducted on a palliative care unit of a university-affiliated teaching hospital in central Canada. This unit has thirty-five patient bed capacity, and admits approximately 300 patients per year. The majority of patients have a diagnosis of terminal cancer, although occasionally, patients with other end-stage disease (e.g. heart failure) are also admitted. Due to increasing volumes of patients requiring admission to hospital, five beds of the total intended for palliative care patients became designated for use of acute medical patients during the tenure of this study. This mix resulted in acute medical patients and palliative patients being housed on the same unit. However, medical patients were followed and managed by their own physicians, while palliative care patients were managed by palliative care physicians.

The palliative care unit though similar in physical layout to other units within the hospital had a decidedly warm and home atmosphere about it. This was accomplished in part by some of the decor and furnishing on the unit. Art work in every shape, color, size, and media imaginable adorned the walls of this unit. Small plaques affixed to these works frequently indicated that they had been donated to the unit by family members in memory of their loved one who had died there. The "art collection" on the unit is so extensive that the surplus is stored in the office of the unit Liaison Nurse (much to her chagrin).

A common area or family room is located approximately two thirds of the way down the hall from the nurses desk. Immediately upon entering this room, one finds a restaurant style coffee machine, and freshly brewed coffee always available for family and visitors. The room contains two sofas and an assortment of occasional chairs arranged in a living-room like configuration. A television and stereo were also present in this room. The stereo was on most of the time during the day and evening, softly playing classical music, and an upright grand piano graced the room's east wall. A tiny table suitable for toddlers and small children was also located in this room along with a collection of toys, books, and magazines. Well tended plants (usually in bloom) always lined the ledge of the north facing window of this family room.

On the west wall of this room was found a small kitchen like area consisting of a refrigerator, microwave oven, sink, and electric kettle. The cupboards in the kitchen area contained packages of cookies, Styrofoam cups, eating utensils, paper napkins, and so on.

Patient rooms were primarily double occupancy, however a few single rooms did exist on the unit. The walls of these rooms were also adorned with art work, and many patient rooms contained objects patients and families had brought in from home that helped to personalize the space. Small quilts and comforters were seen on the end of many patient beds: these were supplied by the unit to those patients who wished to make use of them.

Two events that occurred regularly on the ward also helped to make the palliative care unit feel less like an institution and more like a home. These included the regularly scheduled Thursday afternoon "tea parties" that were held on the unit, and the visits from a music therapist. The tea parties were coordinated by members of the corp of hospital volunteers. Volunteers would set up small tables near the kitchen area of the family room just described. These tables would be adorned with white linen table cloths and china tea cups and saucers, and plates laden with dainties, cookies, and pieces of cake. Family members, visitors, and staff were invited to partake of tea and cakes. Patients were also invited to attend afternoon tea. If they were not physically able to come to the family room, or preferred to remain in their room, volunteers would bring tea to the patients. In addition to being a pleasant social event, it became evident to the researcher that afternoon tea was also a time wherein family members got to know one another, and talk about their respective experiences on the palliative care unit with each other.

The presence of the music therapist also gave the ward a decidedly non-institutional feel. The music therapist was a man in his late thirties who would wander about the ward playing his guitar softly singing songs to patients and families. Most often, these songs were either folk songs or hymns.

Permission for access to the palliative care unit was secured from the acting Medical Director of the unit, and the St. Boniface Research Access Committee. The investigator has been known to staff on the palliative care unit since 1993 when she was in the role of a part-time Research Nurse. More recently the investigator has been affiliated with the unit through her academic position at the University of Manitoba, and teaching responsibilities in the area of adult palliative care.

Sampling, Inclusion Criteria, and Recruitment Procedures

The sample recruited for the study, rationale for inclusion, and inclusion criteria will now be detailed. Consistent with the aims of grounded theory research, a theoretical non-probability purposive sampling technique was used. This approach is appropriate, given that the purpose of grounded theory is to detail the many facets of a phenomenon, and that the researcher is concerned with the representativeness and saturation of emerging themes and concepts (Lincoln & Guba, 1985; Strauss & Corbin, 1990). Sampling and data collection procedures for the study were completed over a fourteen month period.

Patients. An initial sample of 10 advanced cancer patients in the terminal phase of illness was initially recruited for the study. The terms "advanced cancer" and "terminal phase of illness" were applied as previously defined in Chapter I. Advanced cancer patients in the terminal phases of illness experience first hand: i) the effect of their disease on their desire and/or ability to eat; ii) family and health care provider responses to their lack of appetite and weight loss; and iii) the consequences of interventions implemented or not implemented by family members and health care providers in relation to nutritional care. As such, they were especially well suited to provide an emic, or insider's perspective (Andrews & Boyle, 1999) on issues related to such care.

Inclusion criteria for patients consisted of the following parameters: i) voluntary consent to participate in the study; ii) a diagnosis of terminal cancer as opposed to another end-stage disease; iii) 18 years of age or older; iv) ability to speak and understand English; v) no evidence of mental confusion as per report of the patient's primary nurse or attending physician and/or during the course of interacting with the researcher. Consistent with the aims of grounded theory sampling began broadly, and became more deliberate on the basis of concepts and relationships emerging from the data. The researcher did return to the field after all data had been analyzed in order to interview three more patients as it was felt that the data from this group of individuals was not complete. This was because the fatigue and symptom distress and acuity of the patients resulted in somewhat shorter interviews than with other informants. However, no new data emerged as a result of these interviews.

Procedure: The Clinical Resource Nurse (CNR), [formerly known as the Head Nurse] on the Palliative Care Unit (PCU) was requested by the researcher to identify potential patient respondents who met study criteria to determine their interest in participating in the study. She then asked interested patients for permission to release their names to the researcher who then personally approached patients to provide further information about the study, and determined their desire to participate in it (See Appendix A) . Patients willing to participate in the study were provided with a written consent form to sign prior to the commencement of data collection (See Appendix B). Past experience conducting research with palliative populations indicated that patients frequently experience troublesome symptoms at the time of their admission to hospital (Kristjanson, Dudgeon, Sloan & Adaskin, 1996). Therefore, patients were not approached to participate in the study within the first 48-72 hours after admission to the PCU. This time frame allowed for some amelioration of acute symptom distress and was deemed to be most ethically sensitive.

Family Members. A sample of 13 family members of advanced cancer patients hospitalized on a palliative care unit (i.e. in-patient families) and 10 bereaved family members who had experienced the death of a relative due to terminal cancer on the palliative care unit were recruited for the study. The sample of bereaved family members did not include any of the individuals who had been recruited as in-patient family participants. For this project, family member was defined as a spouse, adult child, sibling, or parent of the patient, who is identified by the patient or the Clinical Resource Nurse of the Palliative Care Unit as the individual most involved in the patient's illness.

The sampling of in-patient and bereaved family members provided the researcher with descriptions of family member experiences and perceptions regarding nutritional care in terminal illness at two different points in time. Sampling of families in this way added to the density and richness of the model that emerged, as often family members who had previously experienced the death of a loved one had developed additional insights about their attitudes and responses to declining intake, and the role of nutritional care in the patient's overall plan of care.

In-patient family member inclusion criteria consisted of: i) voluntary consent to participate in the study; ii) 18 years of age or older; iii) identified by the patient as the family member most involved in the patient's illness; iv) ability to speak and understand English. Bereaved family member criteria included criteria i- iv as identified for in-patient family members, and the additional criterion of being an individual identified by the Palliative Care Liaison Nurse as being able to discuss his/her experiences in the bereavement period without experiencing undue burden or distress.

It is recognized that one family member's perception of the care situation constitutes a single view point, which must not be construed as a total family perspective which would require more members' views. However, families face multiple stressors during the terminal phase of the cancer experience (Oberst, Thomas, Gaas & Ward, 1989), and undergo both physiological and psychological health changes in response to the stress of a terminal illness in the family (Kristjanson, 1986). Thus while some individuals have criticized palliative care researchers for relying the use of a single family informant (Davies, Chekryn-Reimer, & Martens, 1994) the selection of a single family member may be justified on the grounds of feasibility (Fisher, Terry & Ransom, 1990).

Procedure. The researcher provided the CRN with the names of in-patient family members identified by recruited patients as being most involved in their care. The CRN verified that potential family respondents identified by the patient met the study's inclusion criteria, and approached them to obtain their permission to have their name and telephone number released to the researcher (See Appendix C). The researcher then contacted interested family members, and provided them with additional information about the study. Arrangements were made to set up a mutually convenient date, time, and location at which to meet to conduct an interview. Family members willing to participate in the study were provided with a written consent form to sign prior to the commencement of data collection (See Appendix D).

Due to high levels of cognitive impairment in palliative cancer patients in the final weeks of life (Harlos & Dudgeon, 1994), not all patients were able to participate in the study, and hence could not identify their primary caregiver to the investigator. This situation arose four times in the course of this study. It did not preclude the recruitment of those family members into the study, however. If a patient was found to be too ill or too cognitively impaired to identify a family member, the CRN assumed this identification function. She would then ask permission to release the family member's name and telephone number to the researcher, and the procedure would proceed as described above.

In the case of bereaved family members, the Liaison Nurse for the Palliative Care Program served as the researcher's clinical contact person. The Liaison Nurse routinely telephones family members who have experienced a death on the palliative care unit to assess how the family is managing in the bereavement period. These telephone calls are usually placed two to three months following the patient's death. Guidance from the Consulting Psychiatrist to the Palliative Care Program suggested that it would be ethically sensitive to contact bereaved family members two to three months following the patient's death (Harvey Chochinov, personal communication, May, 1997). This time frame helped to guard against approaching family members who were in the acute phase of grief (i.e. less than one month following the patient's death), and helped to ensure that family members were being interviewed within a period of time that will enhance the likelihood of accurate recall of the patient's care experiences.

The researcher provided the Liaison Nurse with a brief outline of the study to be read to potential participants on the phone (See Appendix E). If the family member was interested in learning more about the study, or if he/she agreed to participate, the Liaison Nurse asked the family member's permission to release his/her name and telephone number to the researcher. Upon receiving this information from the Liaison Nurse, the researcher contacted the family member by telephone to confirm their desire to be a part of the study, and provide further explanation about the project. Arrangements were then made to set up a mutually convenient date, time, and location at which to meet to conduct an interview. Bereaved family members willing to participate in the study were provided with a written consent form to sign prior to the commencement of data collection (See Appendix F).

Health Care Providers. A purposive sample of 10 health care providers working on the palliative care unit was recruited for the study. For the purposes of this study, "health care provider" was broadly defined to include nurses, physicians, social workers, chaplains, and unit assistants. Health care providers on the palliative care unit are confronted with issues and concerns that patients and family members raise about nutritional care practices. Obtaining the perspective of these care providers allowed the researcher to describe and examine the ways in which these individuals respond to nutritional care issues in the face of advanced cancer, and to identify issues related to this care that are particularly challenging.

Inclusion criteria for health care providers consisted of: i) voluntary consent to participate in the study; ii) being regularly assigned to work on the palliative care unit; and iii) assumption of responsibility for some aspect of the patient's care.

Procedure. Disclaimer sheets requesting permission to observe health care providers during weekly care rounds were provided to all health care providers and were made available on the unit during the course of the study (See Appendix G) A verbal explanation of the project was also provided to any staff member the researcher encountered during the course of the project who was not aware of the study. Health care providers meeting the study's inclusion criteria were approached by the researcher directly to determine their interest in participating in the study. Arrangements were made to set up a mutually convenient date, time, and location at which to meet to conduct an interview. Health care providers willing to participate in the study were provided with a written consent form to sign prior to the commencement of data collection (See Appendix H).

Data Collection

The data collection procedure used during the study will now be described. While patients, families, and health care provider interviews constituted the major source of data, a variety of data collection techniques consistent with the grounded theory approach were used. These included face to face interviews, participant observation, and a review of the patient's chart.

Interviews

Interviews were an important method of data generation in this study. Open-ended, semi-structured, face to face interviews were conducted at mutually convenient times in mutually convenient places with patients, in-patient family members, bereaved family members and health care providers. Semi-structured interviews are described by Polit and Hungler (1991) as those that are organized around a particular area of interest, while still allowing considerable flexibility in scope and depth. The face to face nature of the interaction also affords the researcher the immediate opportunity to ask participants to elaborate upon and/or clarify comments made during the interaction.

Unlike the structured interviews that are frequently used in survey and theory testing research semi-structured interviews are more commonly used in qualitative research as they afford participants the opportunity to "fully explain their experience of the phenomena of interest" (Streubert & Carpenter, 1999, p. 23). The underlying goal of discovery inherent in qualitative research assumes that the salient features of a topic have yet to be revealed. Since these parameters are unknown to the investigator, it is impossible to devise a predetermined and exclusive list of interview questions in advance (May, 1989). This should not be construed to mean that the researcher approaches the interview in a completely neutral fashion. As May (1989) observed, "investigators have some area of interest in mind at the outset, and their goal is to discover and understand the informant's perspective on that particular aspect of life" (p. 174).

Consistent with the definition of a semi-structured interview, the topic of interest (in the case of this study, nutritional care) was explored guided by some sensitizing questions gleaned from the empirical literature, clinical experience, and observation. These questions constituted the semi-structured interview guide used with participants (See Appendices I through L).

It is important to note that the interview guides developed at the outset of the study underwent revision and became more focused as the study proceeded. This evolution was necessary in order to look for commonalities and differences within and across data sets, and to be able to test preliminary hunches and hypotheses. Comparison questions and generality questions were particularly helpful in this regard. For example in this study, family members were asked, "Some family members think that if their sick relative doesn't eat that they will be uncomfortable. What do you think about that, or how does that fit with you?"

Generality questions were used to help validate assumptions about a range of shared experiences among patients families and health care providers with respect to nutritional care. For example, when trying to explore the reactions of family members to declining intake in their dying relative, family members were asked the question: "The families that I have talked to in this study have told me that they have had lots of different feelings when they see that their loved one is not eating or drinking as much as they used to–Could you share with me the feelings that you have had? Another type of generality question that was asked, this time of Health Care Providers was: Dealing with the anger of families who are accusing you of neglecting their relative because you are not starting and IV must be difficult to deal with. In what ways do you deal with their anger?

Sometimes, abandonment of interview guide questions was necessary in order to allow participants to "go where they wanted and needed to go" in recounting their perspectives about nutritional care. This reality speaks to the challenges that researchers face when trying to balance the goals of the project and the needs of the informant (May, 1989).

A major challenge in interviewing concerns the issue of consistency. Consistency can be understood as the investigator making every effort to ensure that the questions that appear to be important at a given course in the study be asked of as many participants as possible (May, 1989). An important strategy in order to help ensure consistency in this study was that of reviewing previous interviews and field notes in order to remind myself about which questions needed to be followed up on in the next interview.

All but three interviews conducted for the study were tape-recorded. Two of the patients recruited for the study had laryngectomies, but did not have voice modulators. Their voices were thus inaudible, and could not be picked up by the tape-recorder. One family member who readily agreed to be interviewed was nonetheless uncomfortable about having her voice recorded. In each of these three cases, the researcher took extensive notes when recording the answers to questions asked during the interview.

Patients were most often interviewed in their rooms, either in bed, or in a chair at the bedside. Two of the patients who were slightly more ambulatory were interviewed in an empty office on the PCU. Interviews ranged in length from 10 to 40 minutes. Patient fatigue and the appearance of distressing symptoms such as pain, nausea, and shortness of breath necessitated terminating patient interviews earlier than the researcher had planned. This occurred in 6 of the 10 patients interviewed. Increasing symptom distress, and the appearance of delirium made it impossible to return to 4 of these 6 patients at a later time to complete the interview, and the remaining two patients expired.

Four in-patient family members were interviewed in an empty office on the PCU, while the rest were interviewed in their homes, as were all bereaved family members. Family member interviews (both in-patient family and bereaved) ranged from 1 and ½ to 3 hours in length.

Except for one staff member who preferred to be interviewed at home, all health care providers were interviewed in an empty office either on the PCU, or somewhere else in the hospital. Health care provider interviews ranged from 35 minutes to 3 hours in length. When interviews were conducted during working hours at the hospital, I as the researcher felt more conscious of the time, and was worried that I was taking staff away from the more important work of patient care. This feeling of being a "clock watcher" when conducting interviews during the course of a health care provider's work day has been noted by other researchers (Reimer-Kirkham, 1999). However, consonant with the experience reported by Reimer-Kirkham (1999), because the nature of my relationships with palliative care staff were already fairly well established prior to the onset of the study these interviews flowed easily and contained thick description even if at times they were somewhat shorter, or interrupted because of the need of the staff member to tend to something on the unit.

Demographic data was obtained from all participates in order to describe the sample (Demographic Forms: See Appendices M through P). In order to obtain information about the patients disease status, patients' charts were accessed following the securing of either patient of family member permission to do so.

Participant Observation

Participant observation is an observational technique in which the researcher becomes a participant in the situation being observed (Dempsey & Dempsey, 2000, p.

368). As such it serves to complement and /or challenge data generated in interviews, and in so serves as a method of data triangulation (Knafl & Breitmayer, 1989).

The literature describes the act of participant observation in terms of the amount of participation engaged in by the researcher in the field (Dempsey & Dempsey, 2000). This participation can range from researcher as complete observer (i.e. wherein the researcher does not interact with participants, but acts as a full observer to their activities) to the ethically questionable stance of complete participant (i.e. wherein the researcher fully observes and participates in the activities of participants, but the purpose for doing so is concealed (Streubert & Carpenter, 1999).

The type of participant observation engaged in by the researcher during this study was that of observer as participant. In the observer as participant role, the researcher's main focus is on that of observing and interviewing. Steubert and Carpenter (1999) noted that "to fit into the setting, the researcher may engage in some activities with the participants" (p. 25). This did occur during the course of the study. For example, the researcher would sometimes help reposition patients in bed to make them more comfortable, answer the ward telephone and help hand out meal trays on the unit. However, the bulk of my time was not spent becoming involved in specific activities of the participants.

Participant observation activities involved attending such regularly occurring events as change of shift report, interdisciplinary patient rounds, and death reviews. No predetermined interview schedule was used in collecting observations from participant observation activities. Part of this is a function of the phases or stages reported in literature within which observation unfolds during field work (Adler & Adler, 1994; 1980). Consistent with these phases, my initial observations tended to be more general and unfocused at the outset of the project, becoming more selective and focused when my goals were to further explicate conceptual categories, add theoretical density, and achieve saturation.

Observational data was typically recorded on a small note pad that the researcher brought with her into the field setting. Notations were made as soon as possible after a period of observation–either in an unobtrusive place on the unit (such as an empty patient room or empty conference room) or at home. Typically these notations were rather brief and contained key words or ideas to help the researcher construct a more detailed account of the observation at a later time. I initially felt quite awkward jotting brief notes during interdisciplinary care rounds, and tended to hold the notebook on my knee, almost under the conference room table. My intent was not to shield my activities from participants, as indeed they were aware of my purpose on the unit and the intent of my note taking activity. Ironically, over time, some members of the health care team would make the comment to me during team meetings, "Sue, this is important for your study, are you getting this down?"

Indeed, like interviews, field notes data constituted an important data source for the study. Moreover, as Emerson and colleagues (1995) noted, participant observation and the act of writing field notes are not distinct but interdependent activities. That is, "writing field notes helps the researcher to understand what he has been observing in the first place, and, thus, enables him to participate in new ways, to hear with greater acuteness, and to observe with a new lens (p. 15). The importance of writing up detailed field notes based upon notes jotted in the field as soon as possible following periods of participant observation cannot be overstated. The researcher did make a concerted effort to follow this edict, generating more elaborate field notes, raising questions, and making theoretical notations as soon as possible after the observational period. However in some instances researcher fatigue and competing demands and responsibilities precluded this from happening. A strategy implemented to help ensure available time for the generation of field notes was that of shortening the amount of time spent in the field, and not scheduling subsequent interviews or observational periods until the notes were done.

Chart Review

Information was collected from palliative cancer patient's charts as it related to: a) the patient's diagnosis; b) documentation of troublesome symptoms, with particular emphasis on those symptoms that had the potential to impact on the patient's ability to eat and drink; c) delineation of the patient's plan of care, particularly regarding interventions related to nutrition and hydration; and d) documentation made by members of the health care team regarding interactions with the patient or family about nutritional care issues.

The data from patient charts were reviewed with the purpose of identifying any discussion or documentation about health care provider perspectives of the patient's nutritional status and to obtain a sense of the salience placed on nutritional care in the overall written plan of care. Charts were also reviewed to track documentation of any discussion that may have occurred between the patient, family, and health care provider about nutritional care issues, and served as a method of cross-validating actions and information eluded to during participant interviews.

Data Management

The data generated from interviews, field notes, and chart reviews were managed in the following fashion. The audio-cassette tapes used during interviews with patients, families, and health care providers were stored in their original case, along with information pertaining to the date of the interview, and the code number assigned to it. Transcribed interviews were stored on the computer hard drive, backed up with two floppy disc versions of the data. Two hard copies of interview transcripts of the tapes were printed-a working copy for coding, and a clean copy. Working copy transcripts were filed in chronological order in a series of binders, whilst clean copies were stored in the same fashion in sealed envelopes. Field notes were also stored on the computer hard drive with disc backup. All raw and coded data was kept in a locked filing cabinet in the researcher's office during data collection. Consent forms were also secured, kept in a locked drawer separate from other data.

Data Analysis

All tape-recorded interviews were transcribed verbatim. Data from the interviews, field notes, and patient charts were analyzed using the constant comparative method. Passages of data were reviewed within the context of the entire interview or field note in order to identify and code the intent of the section and to extract the meaning within the context. The researcher moved back and forth among the data sets, comparing each bit of data to all other data. In this way, the researcher was able to discover the presence, absence, or variation of patterns in the data (Wilson, 1989). Data collection and coding proceeded simultaneously. Analysis proceeded through the stages as outlined in Chapter III. Categories were deemed to be saturated when no new information on the characteristics of the category was forthcoming (Schatzman & Strauss, 1973). Operational definitions were written for all major categories. Descriptive statistics were used to describe the sample in terms of demographic characteristics and patient disease states (See Tables 1 , 2, and 3, pages 71-76).

Ethical Considerations

Prior to the onset of data collection, permission to conduct this study was obtained from the Ethical Review Committee, Faculty of Nursing at the University of Manitoba, and the Access Committee at the St. Boniface General Hospital (See Appendix Q). Protecting the human subjects who participate in one's research project is an important consideration for any investigator, and it is the researcher who bears the ultimate responsibility for conducting research in an ethical manner (Calman & Hanks, 1995). To that end, three basic principles need to be addressed when conducting research with human subjects. They are: i) the principle of respect for human dignity; ii) the principle of beneficence; iii) the principle of justice (Dempsey & Dempsey, 2000). How were these principles addressed within the context of this study?

The principle of respect for human dignity, refers to an individual's right to self-determination and to full disclosure. This principle requires that the researcher treat all participants as autonomous beings with the capacity to voluntarily chose whether or not they wish to participate in a study. To that end, all individuals meeting the study's inclusion criteria were approached and given the opportunity to take part in the project.

Some critics may object that it is unethical to conduct research on dying patients and/or their family members because such individuals constitute a vulnerable group. While this researcher acknowledges that these individuals are indeed vulnerable, she also agrees with the following statement made by Kristjanson and Balneaves (1994) regarding research in palliative care populations:

> "...as an autonomous being worthy of respect, a dying person has the right to decide whether or not to participate [in research]. Staff and researchers then have a moral obligation to respect his or her decision. Indeed, they would be acting in accordance with a paternalistic stance if they categorically stated that no dying patient should participate in research studies (p. 11).

The notion of informed consent requires that potential participants receive correct and sufficient information about a study in order to be able to decide whether or not they wish to participate in it. (Behi & Nolan, 1995). To that end, the following procedures were observed. All participants received an explanation of the study from the researcher, first verbally, and then in writing as outlined on the consent form. After having the opportunity to hear and read about the purpose of the study and the nature of their involvement in it should they choose to participate, individuals were encouraged to ask for additional explanations and to seek clarification should they so desire.

Inherent in the principle of respect is the recognition that some individuals may lack the capacity for self-determination (Dempsey & Dempsey, 2000). In this study, the presence of cognitive impairment had the potential to render some patients incapable of being able to fully understand the purpose of the study, let alone consent to take part. For this reason, individuals demonstrating evidence of such impairment were excluded from the study. Moreover, given the fluctuating nature of cognitive impairment that can occur in terminal cancer patients, the researcher carefully assessed for the presence of cognitive impairment during the course of interviewing the patient. In the event that such impairment was detected, the researcher had plans to terminate the interview and withdraw the patient from the study. No such instances occurred during the course of data collection with patients during this project.

The principle of beneficence, that is, the right to freedom from harm and exploitation, requires that the researcher treat each participant in such a way as to do no harm to that participant (Kemp, 1999). In studies where risk/harm are unavoidable, the researcher is duty bound to minimize them. Every effort was made to maintain the well-being of participants in this study. First, patients were not approached to participate in the study until it was clear that the symptom distress that precipitated admission had abated. Second, in the event that either patients, family members, or health care providers became upset during the course of being interviewed, the researcher planned to temporarily suspend questioning, provide emotional support to the individual, and give them the opportunity to decide whether or not they wished to continue with participation in the study. Past experience interviewing patients and families in the palliative care setting had taught the researcher that there is usually a great deal of emotion that lies directly below the surface in these individuals, and that tears and sadness frequently get expressed during interview sessions. This was indeed the case in this study. Three of the patients appeared somewhat sad when talking about their experiences. Every in-patient family member became either teary and/or cried openly when being interviewed, as did all but one bereaved family member. None of the patient or family member participants indicated that they wanted to terminate the interview when given the opportunity to do so, and many commented that it was helpful to be able to "talk about things".

Only one health care provider interviewed for the study became teary when recounting a situation in which she felt the nutritional care the patient received was tortuous for him. The emotional reaction most commonly seen in health care providers were feelings of frustration in dealing with "difficult families", and anger in reaction to the interference of other members of the health care profession who sought to, or actually disrupted the plan of care that was in place for the patient. In the event that a health care provider had become extremely upset or distraught, the procedure outlined for patients and family members would have been followed by the researcher.

The principle of justice, that is, the right to fair treatment and privacy demands that all individuals taking part in the study be treated in a fair and equitable manner, with assurances of anonymity and confidentiality (Kemp, 1999). In this study, participants were assigned a code number, and their name did not appear on any of the data they provided. Any names mentioned during the interview were replaced with pseudonyms. For example, if the specific name of a patient was mentioned by staff, their name would be replaced with Patient X. Participants were also assured that any information they shared during the course of the interview would be kept confidential. This assurance was given to participants verbally by the researcher prior to the interview, and appeared in writing in the consent form. Moreover, subjects were also advised that their names would not be used in any publication or report emanating from the study, and that data would be reported in aggregate fashion to help further protect the identity of specific individuals.

Reliability and Validity of Data: The Rigor of Qualitative Research

Cormak and Llandaff (1991) appropriately asserted that if research is to be of any value, the issues of reliability and validity must be addressed. This assertion thus begs the question, "to what extent has this grounded theory study generated a worthwhile end product?" Such a question requires that the researcher be able to demonstrate the degree to which this work demonstrates specific criteria that incorporate the concepts of validity and reliability specific to naturalistic inquiry (Woods & Catanzaro,1988). In a grounded theory, validity refers to the usefulness of the conceptual framework that has been generated. The findings are deemed to be valid when the framework developed is well integrated, easy to understand, explain the major variation in phenomenon studied, (Stern & Pyles, 1986).

Given that the purpose of this grounded theory study was theory generation as opposed to theory testing, the criteria for assessing the validity and reliability of a study are, of necessity, different from those criteria used to evaluate the rigor of quantitative research (LoBiondo-Wood & Haber, 1991). The four criteria identified by Lincoln and Guba (1985) will be applied here to evaluate the rigor of this qualitative work. The criteria include: 1) credibility; 2) applicability; 3) consistency; and 4) neutrality.

Credibility

The criterion of credibility refers to the extent to which the reviewer of a study can place confidence in the truth of the findings, and trust that multiple constructions of reality have been adequately represented. Credible studies are characterized by accurate or faithful description, portrayal, and interpretation of the experience under examination. Sandelowski (1986) asserts that the findings of a study are deemed to be credible when individuals going through a similar experience as the participants in the study readily recognize and identify with the analyst's interpretation of the data. Techniques advocated by Lincoln and Guba (1985) were used in this study to help enhance the credibility of the findings.

First, the researcher spent prolonged time in the field during the study which facilitated the development of a trusting relationship with health care providers on the palliative are unit. Data collection occurred over a period of fourteen months.

Second, persistent observation of patients, families, and health care providers interacting with each other about nutritional care issues over time helped to provide salience and depth to the findings, and sort out typical from atypical events.

Third, triangulation of data sources and data collection methods were used in the research process, and served to cross-validate findings. Triangulation refers to the researcher's efforts to "capture a more complete, holistic, and contextual portrayal of the unit(s) under study" (Jick, 1983, p. 183). Conceptualized in this way, the researcher uses multiple sources of data to contribute additional pieces to the puzzle with an aim toward the goal of completeness (Knafl & Breitmayer, 1989).

Fourth, member checks were carried out in which participants were given the opportunity to react to my analysis. The process of debriefing with members of my advisory committee provided further opportunity for analyses to be challenged and defended, or subsequently retooled and refined.

Transferability

The criterion of transferability refers to the extent to which the findings of the study are applicable and meaningful when applied to other settings with other participants (Lincoln & Guba, 1985). It has been argued that researchers can never be certain of the degree to which the findings in one context will be similar in another (Lincoln & Guba, 1985). In this study the researcher probed participants to describe the data in great detail whenever possible. The generation of thickly described data facilitates the possibility of attempting verification of these study findings in another context (Woods & Catanzaro 1988). Major themes emerging from the data were presented to local and national palliative care clinicians from institutions during last year's national Palliative Care Conference in London, Ontario. That those themes appeared to resonate with the experiences of palliative care clinicians from different parts of the country suggested that the findings of the study are credible, and that there was some degree of "fit" and transferability between findings from this study and other palliative care settings.

Auditability

This criterion refers to the extent to which a researcher not associated with the project can trace and follow the way in which study events have progressed and unfolded and track the decision-making processes used by the researcher. To that end, the steps of the research process and all decision making points related to the study were documented in the researcher's field notes. Decision making related to analysis issues were documented in the theoretical notes and memos, and in the notes the student made following meetings with advisory committee members wherein emerging themes were discussed. It is critical to note here, however, that due to the fact that reality is "co-constructed" between researcher and subject in the moment, qualitative research studies cannot be "replicated" in the same way that quantitative work can (Wilson, 1989). However, other researchers following the detailed plan of a previous conducted study should arrive at conclusions that are similar to, as opposed to being in direct opposition or conflict with that of the original work.

Confirmability

The criterion of confirmability addresses the extent to which the findings of this study are in fact reflective of the subjects' experiences and not that of the biases of the researcher. In order to address this issue, the researcher took care as much as possible to use the participants own words when coding data and generating major categories. Assumptions underlying the study were articulated by the researcher at the outset of the project, and reflexive field notes were kept as a check on the assumptions and perceptions of the researcher regarding the data. As noted by Lobchuk (1999), the process of keeping personal notes or a diary about research experiences with cancer patients and family members, allows one to critically reflect on the "bigger picture". As is advocated in the literature (McIntyre, 1997), the journaling of these experiences in notes or a diary helped to acknowledge and catalogue initial reactions I experienced to persons, places, and events with an aim to being honest about the fact that these emotions and reactions were operating and had the potential to influence my perception. Acknowledging the existence of these feelings and responses was not only cathartic, but essential in helping me retain a sense of perspective, and, as noted by Lobchuk (1999), "helps to free the researcher from encumbrances that may pose threats to the study, such as loss of objectivity, burn-out due to ongoing diligent attention to data collection, or over-identification with respondents" (p.71).

Summary

This chapter provided a description of the methods and procedures used in conducting the study. Approaches to sampling, data collection, and analysis were discussed and ethical considerations examined. Steps to ensure the scientific quality or rigor of the research were outlined. The following chapters detail the findings of the study.

CHAPTER FIVE:

STUDY FINDINGS: DOING WHAT'S BEST

Introduction

An overview of the model that emerged from the data describing how families balance the means and goals of nutritional care while fulfilling their own needs and goals related to the provision of such care is presented in this chapter. Characteristics of the sample are also described. Subsequent chapters will provide a more detailed description of each of the model's components.

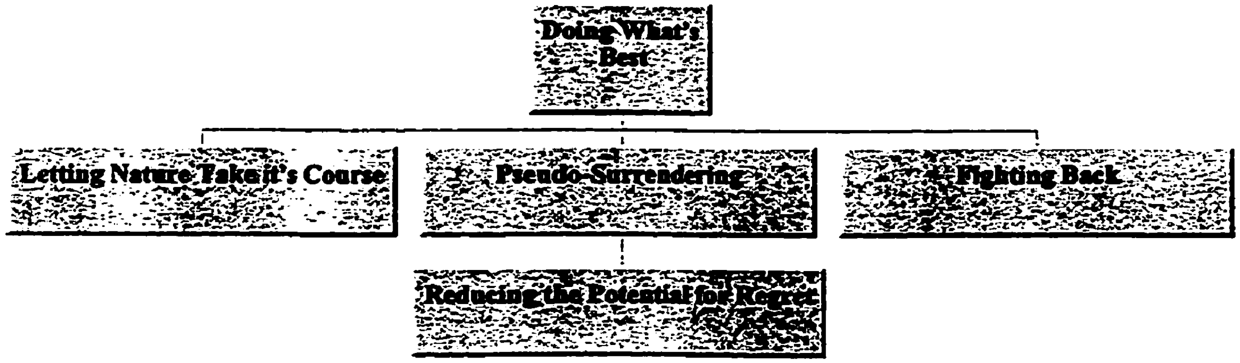
Doing What's Best: An Overview of the Model

Grounded theory coding methods enable researchers to identify the basic social psychological process (BSP) that occurs in response to a basic social psychological problem. A basic social psychological problem refers to a pattern of behavior which is both relevant and problematic for individuals in a given situation (Fagerhaugh, 1990). A BSP is a type of core category that emerges from the data which accounts for as much variation in behavior as possible, and uses as few concepts as possible (Strauss & Corbin, 1990).

During the course of data collection it became evident that the basic social psychological problem experienced by the family members in this study was that of balancing the means and goals of nutritional care for their terminally ill relative while fulfilling their own personal needs and goals related to the provision of such care. The basic psychosocial process (BSP) that emerged in response to this problem was that of "doing what's best." "Doing what's best" was the process that families engaged in to help ensure that the nutritional care they deemed optimal in order to achieve their desired goal was received by the patient. An overview of the main components of the model are presented below in Figure 1.

Figure 1. Model Overview

Basic Social Psychological Process (BSP):
Doing What's Best



Intervening Conditions

1) family members' perceptions regarding the cause of the patient's decreased intake and declining status; 2) family members' perceptions about the nature of palliative care; 3) family members' appraisal of the burdens and benefits of interventions to support declining intake; 4) information; 5) past experience; 6) readiness to let go of the dying individual; and 7) the symbolic meaning of food.

"Doing what's best" was manifested in the form of strategies or sub-processes that had families: i) "fighting back: it's best to eat"; ii) "letting nature take its course: it's best not to eat"; and iii) "pseudo-surrendering". The consistently appearing strategy used by family members who were "fighting back" as a means of doing what's best was captured under the major category of "getting calories in". Three main actions or behaviors were associated with this strategy. They were: i) targeting the patient; ii) manipulating food; and iii) targeting the health care provider.

Three sets of conditions were associated with the use of strategies designed to get calories into the patient. As such, these conditions provided the context within which actions and behaviors associated with "fighting back" were carried out. First, family members who were "fighting back" tended not to view decreased nutritional intake as an inherent and expected part of the dying process. Second, they felt that decreased intake was largely responsible for the patient's declining status as opposed to the progression of the disease. Third, fighting back families believed that there were efficacious ways to intervene to enhance the patient's nutritional state and improve the patient's decline.

In contrast, the strategy embraced by families who were oriented toward "letting nature take its course", was captured under the major category of "finding other ways to care." The three main actions or behaviors associated with this category included: i) participating in physical care; ii) being there; and iii) protecting. The following conditions provided the context within which actions and behaviors associated with letting nature take its course were enacted. First, families who adopted this position expressed the belief that declining intake in food and fluid was a normal occurrence at the end of terminal illness. Second, they realized that the patient's decline was due to multiple factors, not just minimal consumption of food and fluid. Finally, these families believed that the initiation of interventions designed to augment nutrition or hydration were futile in altering the outcome of the patient's terminal disease.

The strategy embraced by family members who were "pseudo-surrendering" as a means of doing what's best, was captured under the major category of "holding on while letting go". Two main actions were associated with this category: i) cognitive waffling; and ii) behavioral waffling. Families who were pseudo-surrendering were struggling with trying to reconcile the tensions between the position that declining intake of food was both normal in a dying patient, and yet something that they wanted to intervene against. They were wrestling with the realization that the patient's decline was due in part to decreased nutritional intake, but also to the ravages of their disease. Finally they were trying to reconcile the realization that interventions capable of augmenting fluid and food intake could be both beneficial and burdensome to the patient.

Seven intervening conditions influenced which strategies related to "doing what's best" family members embraced, and the extent to which they might move back and forth between sub-processes . The term intervening conditions refers to " the broad and general conditions bearing upon action/interactional strategies (Strauss & Corbin, 1990, p. 103). In this study, the intervening conditions that either facilitated or constrained the use of the strategies previously outlined were: 1) family members' perceptions regarding the cause of the patient's decreased intake and declining status; 2) family members' perceptions about the nature of palliative care; 3) family members' appraisal of the burdens and benefits of interventions to support declining intake; 4) information; 5) past experience; 6) readiness to let go of the dying individual; and 7) the symbolic meaning of food.

The strategies taken by family members in response to declining intake in their dying relative were associated with certain outcomes or consequences. In this study, the overarching consequence of doing what's best, whether that be "letting nature take its course", "pseudo-surrendering " or "fighting back", was the reduction of decisional regret in family members. Decisional regret refers to the remorse and residual feelings of guilt and distress experienced by family members when they perceived that the "wrong course of action" had been taken in response to the patients declining nutritional status. More specifically, family members who opted to "let nature take its course" reported that they: i) felt relieved that they no longer had to struggle to get the patient to eat; ii) felt comforted that they were respecting the wishes of the patient; and iii) took solace in the belief that this course of action afforded the patient optimal physical and psychological comfort.

In contrast, not being able to "let nature take its course" when that was the desired course of action resulted in family members feeling that the patient experienced unnecessary physical and psychological distress as a result of interventions, and that these interventions needlessly prolonged the dying process.

Family members who embraced the "fighting back" approach indicated that adopting that particular stance helped to make them feel that: i) they had done everything that they could to help the patient survive as long as possible; and ii) that their course of action afforded the patient optimal physical and psychological comfort. When family members were not able to fight back in the way that they desired they felt guilty, and expressed concern that not intervening would result in an uncomfortable and hastened death.

Family members who were "pseudo-surrendering" in essence, had a foot in each camp and thus experienced some of the consequences of each. That is, being engaged in behaviors that were consistent with both fighting back and letting nature take its course afforded family these members the best of both worlds. They were able to experience the reduction of decisional regret because the gamut of their behaviors although seemingly, contradictory, was defensible. However, the major consequence of pseudo-surrendering appeared to be the forestalling of having to make a definitive decision about what it was that was best to do in light of the patient's declining intake and deteriorating status.

A detailed description and explanation of each component of the model will be detailed in the following chapters. These chapters will present data as it relates to: i) a description of each of the sub-processes of "doing what's best"; ii) the strategies and behaviors associated with each sub-process; and iii) the consequences of these strategies. The intervening factors that facilitated and/or constrained the use of the strategies in each phase will also be discussed. In this study, as is typical in grounded theory work, intervening conditions influenced the action/interactional strategies taken by family members, and the consequences of action/interaction at one point in time constituted intervening conditions or context at another point in time (Strauss and Corbin, 1990). Thus while the study findings are presented in separate sections in order to present the components of the emergent model in as clear a manner as possible, it must be noted that there is considerable interplay between these component parts.

Characteristics of the Sample

Demographic information describing the study sample is presented in Tables 1-3, pages 70 to 74.

Table 1. Demographic Profile of Patients (N=13) and In-Patient Family Members (N=13)

Characteristic	Patient	Family Member
Age		
18-30	—	—
31-50	1 (7.6%)	6 (46.%)
51-65	3 (23%)	3 (23%)
>65	9 (69.2%)	4 (30.7%)
Gender		
Male	3 (23%)	1 (7.6%)
Female	10 (76.9%)	12 (92.3%)
Education		
Grade 8 or less	2 (15.3%)	—
Some high school	3 (23%)	5 (38.4%)
High school diploma	2 (15.3%)	2 (15.3%)
Some university	2 (15.3%)	4 (30.7%)
University degree	1 (7.6%)	2 (15.3%)
Missing data	2 (15.3%)	—
Occupation		
laborer	—	—
clerical	1 (7.6%)	1 (7.6%)
professional/mgmt	1 (7.6%)	5 (38.4%)
retired	11 (84.6%)	7 (53.8%)
homemaker	—	—
other	—	—

Table 1 (Continued)

Characteristic	Patient	Family Member
Income		
<$10,000/yr	—	—
$11,000-$20,000/yr	2(15.3%)	1 (7.6%)
$21,00-$30,000/yr	2 (15.3%)	2 (15.3%)
$31,000-$40,000/yr	2 (15.3%)	2 (15.3%)
$41,000-$50,000/yr	2 (15.3%)	2 (15.3%)
$51,000-$60,000/yr	1 (7.6%)	3 (23%)
$61,000-$70,000/yr	1 (7.6%)	1 (7.6%)
> $70,000/yr	—	1 (7.6%)
Relationship to Patient		
daughter		8 (61.5%)
son		—
spouse		2 (15.3%)
sibling		1 (7.6%)
parent		1 (7.6%)
other (sister-in-law)		1 (7.6)
Marital Status		
married	9 (69%)	10 (76%)
divorced	—	1 (7.6%)
widowed	3 (23%)	2 (15.3%)
never married	1 (7.6%)	—
common-law	—	—
Ethnicity		
European	3 (23%)	7 (53.8%)
British Isler	5 (38%)	4 (30.7%)
French	1 (7.6%)	—
Asian	—	—
Other	2 (15.3%)	—
Religion		
Catholic	3 (23%)	5 (38.4%)
Protestant	4 (30.7%)	2 (15.3%)
Jewish	—	—
Other	—	1 (7.6%%)
No affiliation	3 (23%)	5 (38.4%)

Table 1. (Continued)

Characteristic	Patient	Family Member
Patient Diagnosis		
Bowel cancer	4 (30.7%)	—
Cancer of the larynx	3 (23%)	—
Lung cancer	2 (15.3%)	—
Brain cancer	1 (7.6%)	—
Breast cancer	1 (7.6%)	—
Renal cancer	1 (7.6%)	—
Stomach cancer	1 (7.6%)	—

Table 2. DEMOGRAPHIC PROFILE OF BEREAVED FAMILY MEMBERS (N=10)

Characteristic	Bereaved Family Member
Age	
18-30 yrs	---
31-50 yrs	2 (20%)
51-65 yrs	5 (50%)
>65 yrs	3 (30%)
Gender	
Male	2 (20%)
Female	8 (80%)
Education	
Grade 8 or less	1(10%)
Some high school	2 (20%)
High school diploma	1 (10%)
Some university	4 (40%)
University degree	2 (20%)
Occupation	
laborer	—
clerical	1 (10%)
professional/management	—
retired	8 (80%)
home maker	—
other	1 (10%)

Table 2. (Continued)

Characteristic	Bereaved Family Member
Income	
< $10,000/yr	1 (10%)
$11,000-$20,000/yr	1 (10%)
$21,000-$30,000/yr	1 (10%)
$31,000-$40,000/yr	—
$41,000-$50,000/yr	1 (10%)
$51,000-$60,000/yr	2 (20%)
$61,000-$70,000/yr	—
>$70,000/yr	—
Declined to answer	4 (40%)
Relationship to Patient	
daughter	3 (30%)
son	—
spouse	6 (60%)
sibling	—
parent	—
other	2 (20%)
Marital Status	
married	3 (30%)
divorced	—
widowed	6 (60%)
never married	1 (10%)
common-law	—
Ethnicity	
European	3 (30%)
British Isler	2 (20%)
French	2 (20%)
Asian	1 (10%)
Other	2 (20%)
Religion	
Catholic	5 (50%)
Protestant	3 (30%)
Jewish	—
Other	1 (10%)
No affiliation	1 (10%)

Table 2. (Continued)

Characteristic	
Patient's Diagnosis	
Brain cancer	3 (30%)
Colon cancer	3 (30%)
Cancer of the kidney	1 (10%)
Multiple myeloma	1(10%)
Liver cancer	1 (10%)
Breast cancer	1 (10%)

Table 3. DEMOGRAPHIC PROFILE OF HEALTH CARE PROVIDERS (N=11)

Characteristic	Health Care Provider
Age	
18-30 yrs	—
31-50 yrs	7 (63.6%)
51-65 yrs	4 (36.3%)
>65 yrs	---
Gender	
Male	5 (45.4%)
Female	6 (54.5%)
Marital Status	
married	7 (63.6%)
divorced	1 (9%)
widowed	—
never married	2 (18%)
common-law	1 (9%)
Health Care Provider Positions Represented in Sample	
Nursing	36.3%
Medicine	27.2%
Unit Assistant	18%
Pastoral Care	9%
Social Work	9%
Years of Experience Working in Palliative Care	
1-5 yrs	1 (9%)
5-9 yrs	4 (36.3%)
10-14 yrs	3 (27.2%)
15-20 yrs	2 (18%)
>20 yrs	1 (9%)

The final study sample included 13 palliative in-patients, 13 family members of palliative in-patients, 10 bereaved family members, and 11 health care providers. Patients ranged in age from 34 to 84 years with an average age of 69.8 years. The majority of the participants were female (76.9%), and were married (69%). The most common cancer diagnoses represented were those of bowel cancer (30.7%), cancer of the larynx (23%), and lung cancer (15.3%). All patients had been on the palliative care unit a minimum of 72 hours prior to being seen by the researcher. Ten of the 13 patients died within 6 weeks of being interviewed for the study, and one patient died 8 days after being interviewed. The remaining two patients were transferred to other facilities and their date of death from the time of interview is unknown. Four patients who initially agreed to have their name released to the researcher declined further participation upon having the study explained to them. Reasons for refusal included, "feeling too sick", "feeling too weak", "not interested" and "having too much going on right now."

The modal in-patient family member participant was between 31-50 years of age, female, married, and most often the daughter of the patient (61.5%). Three family members who initially agreed to have their names released to the Researcher declined participation after having the study explained to them. Reasons for refusal included, "I don't want to be away from the bedside", "too tired", and "feeling too upset."

The modal bereaved family was between 51-65 years of age, female, and retired. All of the bereaved family members contacted by both the Clinical Nurse Specialist on the Palliative Care Unit and the researcher agreed to participate in the study.

The modal health care provider was between 31-50 years of age and married. Little more than half of the health care provider sample were female (54.5%). Thirty six per cent of the sample had worked in palliative care from between 5 to 9 years, while 27.2% of the group had worked in the area from between 10 to 14 years. Nurses represented 36.3% of the sample, while physicians constituted 27.2%. All but one health care provider approached by the researcher to participate in the study declined, citing reasons of "not having enough time" to be interviewed.

Summary

The basic social psychological problem identified in this study concerned the ways in which family members balance the means and goals of nutritional care in a terminally ill relative, while meeting their own needs in relation to this care. The basic social psychological process that emerged from data addressing this issue was that of "doing what's best." This chapter has provided an introductory overview of the model, its sub-processes, strategies, intervening conditions, and consequences. A description of the study sample was provided. The following chapters will provide a detailed examination of the model's component parts.

CHAPTER SIX:

THE SUB-PROCESS OF "FIGHTING BACK"

Family members engaged in the sub-process of "fighting back" utilized a variety of strategies that were captured under the conceptual category, "getting calories into the patient". The sub-process of "fighting back" its associated strategies, and the consequences of those strategies are schematically represented in Figure 2 below.

Figure 2.

Fighting Back: It's Best to Eat

Main Conceptual Category: ***Getting Calories In***

Associated Strategies:		
Targeting the Patient	***Food Manipulation***	***Targeting the Health Care Provider***
■Vigilant surveillance ■Monitoring & gauging intake ■Coaxing ■Begging ■Bargaining ■Threatening ■Force-feeding	●Bringing in favorite foods from home ●Having food readily available at the bedside ●Offering food frequently ●Adjusting portion sizes	▣ Auditing the plan of care ▣Blaming and accusing staff of providing negligent care ▣ Petitioning staff for additional interventions to support nutrition/hydration status

Figure 2. (continued)

Fighting Back: It's Best to Eat

Consequences Associated with Fighting Back & Getting Calories In for Family Members

→feeling that they had done everything to help the patient survive for as long as possible
→feelings of not having abandoned the patient
→feeling that their actions afforded the patient optimal physical and psychological comfort

Consequences Associated with *not* being able to Fight Back or Get Calories In for Family Members

→ feelings of guilt, anxiety, frustration, incompetence and rejection
→ concern that non-intervention would result in an uncomfortable and hastened death

Consequences Associated with Fighting Back and Getting Calories In for Patients

→anger and frustration in response to being continually barraged to eat
→social withdrawal
→eating to protect the family, sometimes with resultant increased symptom distress

Consequences Associated with Fighting Back and Getting Calories In for Health Care Providers

→feelings of anger and frustration in response to family accusations of negligent care
→having to respond to family anger
→ exploration of family goals and expectations
→initiation of teaching

The behaviors or actions designed to get calories into the patient that emerged from the data included: a) targeting the patient; b) manipulating food; and c) targeting the health care provider.

(a) Targeting the Patient: In this study, "targeting the patient" is defined as family members taking aim at the terminal cancer patient through the deployment of verbal and physical tactics in an attempt to get that individual to eat and drink beyond what they were currently consuming. An integral part of targeting the patient involved family members' vigilant surveillance of the patient's appetite and oral intake. Family members constantly assessed the patient regarding their desire for food, and gauged the amounts and types of food and fluid the patient was taking in:

> *I guess like the last 3 days its sort of been a liquid diet to make it easier, but today, apparently she virtually had no breakfast. And my sister was here at lunch and I think she had a bit of ice-cream, but its [her intake] really declined quite dramatically... (Family Member Interview #7)*
>
> *...like last night, she said she practically ate everything, but at noon today she didn't. She had a couple of teaspoons of soup... (Family Member Interview #8)*

For many family members, this vigilant surveillance occurred right up until the time of death:

> Q: Days before he died, were you worried that he was feeling hungry?
> *A: We asked him, but no. He never felt hungry or thirsty... but I knew at the end he was only taking a little bit and he was using that sign, [for] enough (Bereaved Family Member Interview #2).*

This type of behavior was a natural extension to the type of monitoring and gauging that had been going on regarding the patient's appetite and intake at home, prior to their admission to hospital:

> *I think we did monitor her in a sense... because both my sister and I..we chatted with her frequently and saw her at least once a week. And we would ask her, like we would always ask her. We would talk about what she would have for supper, and we knew she was eating less....We phoned her every night and asked her what she had for super and she would tell us... (Family Member Interview #2).*

Through the act of vigilant surveillance, family members collected important information about their terminally ill relative's intake. The inability to be physically present at the hospital to assess intake and appetite first hand did not preclude family members from maintaining their surveillance. Family members would typically question others who had visited the patient about matters of appetite and intake, and/or telephone the ward and ask the nurse caring for the patient about how well the patient was eating and drinking.

Information about the nature of the patient's intake collected from surveillance activity provided the springboard for subsequent family behaviors associated with targeting the patient in order to get calories in. For example, when family members perceived that the patient's intake was insufficient, a combination of verbal, physical, and psychological tactics would be deployed in an attempt to remedy the situation. Verbal tactics designed to get the patient to eat included coaxing, begging, bargaining and berating:

> *She would have a bite of something, and didn't want any more, so I would say "you have to have a little bit more. You have to get strong if you want to come home, so you have to eat." She would say, "No more, no more." I would just say, "one for me, one for K," her granddaughter..It was a real struggle. I think it was the medication. She would get agitated. (Family Member Interview #6).*

Verbal tactics could also include family members trying to elicit from the patient specific directives about the kinds of food they wanted brought in from home. Family members were often relentless in their questioning of patients regarding what they wanted to eat. Sometimes such questioning would occur, even in the midst of the patient experiencing distressing physical symptoms:

> *I sort of asked her what she wanted [to eat] but then she was in a lot of pain and she didn't want to be thinking about that. But I sort of insisted in her telling me what kind of food I should bring in... (Bereaved Family Member Interview #1).*

Nonetheless, family members believed it was important to obtain such information from patients, as including the patient in decision making about what food was brought was believed to enhance the likelihood that they would in fact eat it once it arrived:

> *I think it's very hard to decide what you are going to give him to eat, you have to ask him what he wants. You can't just make something and say here, you're going to eat that. They have to let you know. You have to ask them what they want... That's the best thing is to ask them what they want because if you make something and they don't like it and won't eat, that's not too good too. (Bereaved Family Interview #2).*

Some family members also indicated that they would verbally threaten the patient with such consequences as going to the hospital and having an intravenous started if their intake did not improve. Such exchanges struck the researcher as being similar to those exchanges that occur when parents attempt to discipline a child, and point out to the child the consequences of behavior that does not conform to parental wishes. First, it was evident during this kind of interaction that the family member was the authority figure, with the patient assuming a more servile role in the exchange. Second, the family caregiver would identify the desirable behavior they wanted from the patient (i.e. increased intake), and outline the consequences if such behavior was nor forthcoming. Interestingly, the family member in the quotation below likened her experiences in "laying down the law" to get her dying relative to eat, to the way one deals sternly with a child when trying to elicit a particular behavior. The notion of the patient being responsible for both causing some of the difficulties with decreased intake, and for helping to remedy the difficulty is also suggested in verbal exchanges that have this more threatening, "consequences oriented" tone:

> *The only thing you can say is that you have to eat something....and you really have to be strict and you have to put your foot down, like when you talk to a kid. You could tell them that if they don't want to eat, then they are going to start feeding you and they are going to give you something through an intravenous. (Bereaved Family Member Interview #9).*

That families would at times threaten patients with undesirable consequences if their intake did not improve was also identified by health care providers in this study:

> *.. Sometimes they do kind of bully them...Like if you don't eat you're not going to be able to come home. I think they just try to bully them so they'll pick up a little strength. (Health Care Provider Interview #6).*

Physical tactics designed to help get calories in included such things as assisting patients with their meals by setting up the tray, and physically feeding the patient. Families indicated that the fatigue and debilitation common in many terminal cancer patients required that assistance with meals be provided:

> *She couldn't do anything for herself at all. That's when I started feeding her and I was up [on the ward] for every meal to feed her. But it took a long time just to get a couple of mouthfuls in. (Bereaved Family Member Interview #1).*
>
> *We did come in at meal times, because she wasn't able to feed herself very well and so we made sure that one of us was here........(Family Member Interview #7).*

At its zenith, "assistance" involved the actual force-feeding of the patient by the family member, whether the patient wanted to eat or not:

> *At first I was force feeding her, making her eat. Then we did get into few little fights....(Family Member Interview #6).*

Families were aware that patients did not appreciate such behavior, but defended the action of force feeding on the grounds that they had to find some way of trying to protect their loved one against the relentless ravages of their disease:

> *I know she doesn't want to eat, but we have to try and give her as much as possible. We try to give her as much as possible, and she just looks at us while we are trying to feed her with a "are you satisfied now?" look. ...We had a little dog who gave us exactly the same look. We had a little dog that wouldn't eat and we continued to force feed it and force feed it until one day it started to eat on its own. Its like that with her, we kept trying to get her to eat, and we try little tricks,*

> *and she knows what we are trying to do and she doesn't like it. Yeah, what can we do? Cancer is like a bulldozer, It goes its own way, but we still have to try. (Family Member Interview #4).*

Interviews with patients corroborated that the verbal and physical tactics used by family member previously described, did occur:

> *Yes, they were pushing me to eat. They would say "eat, eat, eat". But how could I eat when it wouldn't go down? I would just look at the food and I didn't want to eat. (Patient Interview #3).*

Health care providers interviewed for this study also reported that family members could sometimes become quite aggressive with patients where feeding was concerned:

> *We had a patient with a brain tumor. Her husband would actually hold her nose so she would open her mouth to breathe and then put a spoonful of food in her. (Health Care Provider Interview #2).*

> *Yes, they seem to really push them ...sometimes they do kind of bully them. (Health Care Provider Interview #6).*

In addition to using verbal and physical tactics in order to get patients to eat, families also used the strategy of distraction. Providing a diversion from the task at hand was reported as being an effective way of "getting calories in":

> *She has no desire to eat, and she's not hungry now, although if you put something in front of her and distract her, she will eat a little bit. I don't think [the problem with eating] is physical, because like I said, if you distract her, she'll eat. She'll say, "No, I don't want that," but if you are talking to her she'll take it from the plate and she will eat it. (Family Member Interview #13).*

b) Food Manipulation. Another strategy used by family members in their attempt to get calories into the patient was that of food manipulation. Food manipulation refers to the ways in which family members would procure and present food to their dying relative in an attempt to get them to eat. Food manipulation was manifest in a variety of ways. First, family members would frequently bring favorite foods from home in for the patient. It was common place to see family members come to visit the patient, laden with shopping bags full of what they hoped would be tempting fare. The palliative care unit contains a family room and kitchen area where foods brought in from home can be refrigerated and reheated. In the course of conducting field work on the palliative care unit, the researcher frequently looked in the refrigerator to see the type of fare families brought in for patients. Invariably there would be several containers present in the ward fridge, each carefully labeled with the patient's name and room number. These containers could contain anything from gefilte fish to curried pickles. (In some instances, the foodstuff was not recognizable to either the staff or the researcher!). The relational aspects of food brought in from the outside was characterized by one of the health care providers in the following way as touches of home:

> *[They bring in] everything from stuff you don't really know what it is and you don't want to ask. It's a lot of stuff from home and one of the patients here says the soup here is good but its not like my wife's. So its just a matter of the little touches of home. (Health Care Provider Interview #6).*

It appeared that by having favorite foods "at the ready" family members hoped to be able to capitalize on patient cravings, and thus increased the likelihood of getting calories into the patient:

> *...on one occasion I made homemade soup and she really liked that...she didn't ask, cause I would ask her, is there something she would want and she said, "not really". But I brought these things on my own. Cause we asked all the time, and she would just say "no, that's okay". I don't think that she was all that keen on food, no matter what. (Family Member Interview #7).*

Bringing food in from home was only one way of ensuring that sustenance was always readily available. Family members would sometimes take food from the patient's tray that hadn't been eaten and stockpile it, placing it on the patient's over-bed table, bedside bureau, or on the window ledge in the room. Often these surfaces would be quite crowded with containers and cups holding a variety of food and fluids. This "buffet" created by family members also helped to ensure that food was available to the patient at a moment's notice.

A second behavior associated with food manipulation was that of offering food to the patient at frequent intervals. This bereaved family member's comment succinctly encapsulates the strategy of having food at the ready and offering it frequently:

> *Just say, " try this", and be there. Just offer it and have the spoon right there... (Bereaved Family Member Interview #10).*

A third example of food manipulation was the way in which family members would often adjust the portion sizes of food that was offered to the patient. Sometimes this involved presenting just small bits of food at a time, in order to prevent overwhelming the patient:

> *... try something like a spoonful of soft ice cream or mashed banana... Or perhaps that cranberry juice. Just little wee bits of something....(Bereaved Family Interview #10).*

Other times, family members adjusted the portion sizes of food so that the patient received a much larger than a normal sized serving. Sometimes this was accomplished by ordering double portions when helping the patient fill out their hospital menu. Other times, family members would bring double portions of whatever the patient had expressed an interest in, or a craving for, to the hospital. However, these super-sized portions were not always appreciated by patients. Said this man who was dying of lymphoma of his wife's attempts in this regard:

Q: Does she bring you food when she comes to visit?

A: Yes, I had a milkshake, but when I say I want a milkshake, I get 2 of them and I can't handle one, never mind two!! (In-Patient Interview #1).

c) Targeting the Health Care Provider

A third strategy commonly used by family members who were attempting to get calories into the patient was that of targeting health care providers. Targeting of health care providers refers to the interactions families had with palliative care staff in an attempt to procure interventions geared toward enhancing the patient's intake of food and fluid. Specific actions related to targeting health care providers included: i) auditing the patient's plan of care; ii) blaming and accusing of the health care provider (HCP) for the provision of inadequate care; and iii) petitioning the HCP for specific interventions to support the patient's nutritional status.

i) Auditing the Patient's Nutritional Plan of Care

An integral part of targeting the health care provider involved the family member auditing the patient's nutritional plan of care. In this study, auditing behavior refers to the process by which a family member systematically evaluates and compares the nutritional care practices of health care providers against a standard held by the family member as optimal and desirable. Through interviewing family members, it was evident that these family standards regarding nutritional care consisted of two dimensions: 1) levels of acceptable staff performance related to nutritional care, and; 2) levels of acceptable patient outcomes or results. The former dimension involved family members' assessment of staff behaviors as they related to getting calories into the patient, whereas the latter dimension involved family members' assessment regarding such patient outcomes as increased intake, weight gain, and survival.

How did family members collect information for their audit? The primary source of information came from the direct observations made by the family members themselves when they visited the patient in the hospital. For example, interview data and information gathered through participant observation on the palliative care unit indicated that family members were particularly watchful to see if ward staff delivered the patient's meal tray in a timely manner, and whether or not they encouraged and/or assisted the patient to eat and drink. For example, one family member interviewed for the study felt that it was imperative that she come in at meal time to feed her husband, because she had observed that the palliative care staff took his word at face value when he didn't want to eat at mealtimes, and thus would not pursue the matter further:

> *And this one particular day, I came to the hospital and the trays were already gathered up and I looked at his tray and I could see he hadn't eaten. And I guess he just said he didn't want to and no one, you know if he said no, then he wasn't eating...And I talked with the staff people, and we'd say "Well we don't ask him whether he wants to eat. We just say, this is what we are doing now and just carry on. It's a matter of course. This is the ultimatum... So after that, we were there in time to feed him his breakfast.(Bereaved Family Member Interview #10).*

The issue of trust in the health care provider (or lack thereof) was raised by this family member as it related to feeding of patients:

> *... Even though there is a lot of staff here, I'm not sure they would give it to him if I weren't here...but that's partly the reason that I am here because I want it done and I don't really trust them. I think they would do it anyway, but I feel better being here.....(Family Member Interview #9).*

Health care providers were aware that families sometimes harbored concerns that staff would not push food on patients that they did not want:

> *I've had complaints from families that their loved one hasn't been fed. Some family members have decided to come in and feed their loved ones because they feel that not enough food has been offered to their loved one. They come in and they see the tray still there and sometimes unopened sometimes... I've had that complaint and the members take it upon themselves because they think their loved one isn't going to be fed... (Health Care Provider Interview #5).*

However, the act of forcing patients to eat when they did not wish to do so was seen by ward staff as a violation of patient rights and incompatible with "good" palliative care:

> *I say I am not going to force feed anybody and one of my sources of pride on this ward is offering people choices...I am certainly aware of everybody's prognosis here and I don't see how a few mouthfuls is going to enhance this person's last few days or weeks or make their day any more special (Health Care Provider Interview #8).*

The information collected as a result of these care audits enabled family members to make decisions as to whether or not the nutritional care practices they witnessed on the palliative care unit represented "good practice" as they defined it. Moreover, it was clear that family members generated explanations to help identify why the nutritional care practices on the palliative care unit failed to meet the family's required standard. When family members were able to identify the reason or causes for care that they deemed unacceptable, they were then able to tackle the problem in an attempt to solve it. That is, the vital step of identifying why the nutritional care practices of health care providers failed to meet the families desired standard provided an impetus for action.

Family members who were fighting back invariably identified the reasons for sub-standard nutritional care as residing within the health care provider. This resulted in the deployment of subsequent family behaviors associated with targeting the health care provider–namely those of blaming and accusing the health care provider for the provision of sub-standard care, and petitioning the health care provider for additional interventions to augment and support the patient's nutritional status.

ii) Blaming and Accusing the Health Care Provider:

Health care providers interviewed in this study indicated that it was not uncommon to be accused by family members of being negligent regarding the nutritional care of dying patients. They indicated that while concerns about "not eating" were sometimes raised by patients earlier in their illness trajectory, once the patient was in the palliative phase of his or her illness, concerns about "starving to death" was largely a family issue:

> *Q:* Do patients say, "I'm really afraid that I'm going to starve to death. They are not feeding me enough here"?
>
> *A: Not on palliative care. They families are more concerned, not the patients. (Health Care Provider Interview #1).*
>
> *... The issue of nutrition in the early stage, predominantly [is] the patient's worry. We see the patients in the very final stages so its actually the families that are concerned more than the patients. So the issue of not eating is really a family's problem toward the final stage.... it switches over to the family like everything else in the care towards the end we tend to look after the families more than the patients. (Health Care Provider Interview #3).*

When health care providers were accused by family members for providing negligent care, negligence was cast in terms of the failure to provide adequate food and fluid to a terminally ill person. Abandonment of the dying person was also a common theme raised by family members who were fighting back. Family accusations about the failure of health care providers to artificially augment the dying patient's intake of food and fluid were often linked to issues of symptom distress, quality of life, and length of survival, and frequently had the tenor of an ethical objection. The following examples are typical of what health care providers indicated they encountered on a fairly regular basis:

> *Often the statement they'll make is that "he's starving to death"...[they say] things like we are neglecting them or we are letting them die, that sort of thing. I think they often feel if they're not taking any food or fluids and that we aren't encouraging them to take it, then we are just sort of giving up on the person and just letting them die. (Health Care Provider Interview #5).*

Family members interviewed for this study acknowledged that they confronted health care providers about this issue:

> *I did ask the doctor about things, because I don't think you should just let someone starve to death. (Family Member Interview #5).*

The ethical tone of such accusations was not lost on health care providers:

> *[They raise] discomfort, hunger pains, and what not or they are so weak and so fatigued that they can't enjoy quality of life. Outwardly that's quite common the type of issues the families will raise. Others feel that it limits the length or survival and so they will raise that,..... but I think the underlying issues that is probably strongest in all these currents is probably an ethical dilemma... it reduces to the ethics of how can you starve someone to death or allow them to starve to death... (Health Care Provider Interview #4).*

iii) Petitioning for Additional Interventions

In addition to the strategies of auditing nutritional care, and blaming and accusing the health care provider for the provision of inadequate care, families would also frequently petition palliative care staff to institute measures that they (families) believed would help circumvent the problem of decreased intake of fluid and calories, and reverse the signs of physical wasting. The measure most frequently requested by families was that of starting intravenous therapy. Though less common, health care providers indicated that requests to initiate tube-feeding and total parenteral nutrition (TPN) might also be made. Interviews with family members suggested that they equate intravenous therapy with nutritional support, and thus saw an IV as providing a significant source of significant calories. This observation was supported by health care providers:

> *Uhm, the family especially becomes quite upset if there's no IV. Or... they say, "We need an IV here." You know, we're going to starve him to death. Can't we feed him? And I think a thought is that the IV is the magic IV. Everybody has an IV therefore they will live forever. (Health Care Provider Interview #11).*
>
> *Usually, 99% of the time it does come up. What can we give them to eat or drink. What's the best food? What happens when they stop eating? Are you going to start an IV? (Health Care Provider Interview #3).*

Sometimes additional interventions included incorporating complimentary therapies into the patient's plan of care. When speaking of complimentary therapies, it appeared that family members most often referred to health-related products prescribed by the self, family, friends, or an alternative health care provider had suggested or prescribed. In some cases, the alternative health care provider accessed by patients and families might have the authority to prescribe by the Canadian Medical Association, or provincial college of physicians and surgeons. In other instances, they did not. Nonetheless, it was evident in talking with patients and families in this study that complimentary therapy use at home, prior to hospitalization, was fairly commonplace:

> *Oh yes, she was on shark cartilage which was supposed to be good but then she found out she would have to take, I don't know, 25 pills a day to have any benefit. She was on vitamins and some other liquid. A tonic. Whatever she wanted there was no questions about it if you think it helps and if it does help, then it's worth it. Let's try it. (Bereaved Family Member Interview #8).*
>
> *Then she was eating garlic and she was eating so much garlic it wasn't funny anymore. She said eating garlic, it cures the cancer. (Bereaved Family Member Interview #9).*

Some family members reported that they had even taken their dying relative to other parts of the world to receive complimentary therapies:

> *We took her to a clinic in Tijuana. They gave her lots of juices there to help heal her. These were special juices, made with fruits and vegetables and not made with pesticides. They were all organically grown. It was to stimulate her immune system so she could fight the cancer. (Family Member Interview #4).*

It thus was not surprising that families wished to continue with complimentary therapies after admission, and would petition health care providers to sanction their use in hospital:

> *Someone told us about this tea that had a long history. One guy started taking it and he went out golfing the next day, so my husband tried it for the first time. And then when he was told the bad news [about the cancer], he asked the doctor if he could go back on this tea. (Family Member Interview #6).*

Health care providers interviewed for this study acknowledged the frequent use of complimentary therapies by palliative cancer patients. The lack of scientific evidence about the efficacy of such therapies, coupled with the potential for significant financial burden for families associated with their use made some of the palliative care staff interviewed for this study leery of their use:

> *... that's becoming more common...with different kinds of alternatives... We had one gentleman we admitted him very urgently one evening and he was vomiting and this particular diet he was on he was having to eat raw liver and that's what he was vomiting and it was just gross. It was somewhere in Mexico he had been. In Tijuana or somewhere like that and it was an alternative diet that he had been on. It was just horrible... It was designed to give him strength and heal him. His wife was blending the liver and extracting the juices from it and having him drink it. (Health Care Provider Interview #5).*
>
> *I tell them if it isn't going to hurt you, then go ahead. But the cost is something that I get concerned about. I've seen some of these people. They're spending $400 a month on crap, or...well, on stuff that I perceive as being crap. Ah, and you know, shark cartilage for example. Someone's sure making a lot of money on that...And, when people go down to Mexico, they get these magical things. "Oh, I felt better". "I was eating well." We know they're steroids of some sort of another. What else is there?(Health Care Provider Interview #11).*

Consequences of Strategies Associated with "Fighting Back: It's Best to Eat"

The actions and behaviors taken by family members who were fighting back had certain consequences. First, while the intent on the part of the family member in targeting the patient was to get calories in, such actions resulted in some patients feeling angry and upset. This appeared to be due to the fact that for the majority of patients in this study, decreased appetite was of either no importance to them, or held less salience compared to other symptoms they were experiencing:

> *The lady indicated that over time she has experienced a loss of appetite but it didn't bother her because she knew that she was going to die sometime and she doesn't worry about eating. Of more concern to her is the pain she is experiencing in her left knee--she has a lytic lesion on x-ray, and has been referred to a radiation oncologist for pain control. It [not eating very much] has been so long, it doesn't bother me (Patient Interview #8).*

Indeed, some patients saw trying to eat more than their appetite dictated as a self-defeating behavior:

> *...I know you have to have food for nourishment, but you get a certain amount a day...It doesn't require the amount that you used to eat, not in this condition. You'd be full all the time. You'd just be stuffed. (Patient Interview #3).*
>
> *Some people live to eat and some eat to live. Well, I eat to live, I guess. I don't live to eat. I eat what I feel like, I don't stuff it down, because if I do, it would just come back up again...there's no point in that (Patient Interview #9).*

Therefore, being constantly harassed by family members to eat, despite the fact they had no appetite angered patients:

> *The patient indicated that her family members, particularly her son, were quite attentive and fussed around about the fact that she wasn't eating. Several times, especially lately, she has had to tell them to back off. Not to worry so much [Field notes; Patient Interview #8).*
>
> *Uhm, my two daughters-in-law, they said, "Mom, you've got to eat, you've got to eat." And I said, don't bug me. I said I can't eat. (Patient Interview #12).*

Patients reported that their claims of "no appetite", "feeling full" and "feeling nauseous were often simply not believed by family members. This assertion of non-belief was supported during the researcher's interviews with families, and is summed up succinctly by this daughter whose mother was dying of liver cancer and was profoundly anorexic and cachectic:

> *She says she isn't hungry but I'm sure she is. (Family Member Interview #4).*

Even when family members frequently witnessed problems with early satiety and chronic nausea first hand, they could scarcely believe their eyes. This incredulousness is captured in data exemplar below:

> *When she came to the table she would always have a little pail with her and she would say after eating two little Ritz crackers with very little cheese on it, " I feel like I have had a whole meal." And it wouldn't be two minutes and my God! it had come right back up!! (Bereaved Family Member Interview #8).*

Not being believed, and being berated for being an "underachiever" with respect to intake also distressed and angered patients:

> *I'm honest, and if I really feel like it [I'll eat] and sometimes I can't, that's the only time when I don't really eat. When I feel like I just can't. Otherwise, I eat. (Patient Interview #7).*
>
> *My wife was up in the air, really up in the air about me not eating. ...She says she doesn't natter but she sure does. She kept saying , "you got to eat more, you got to eat more.*
>
> Q: Did she make you feel like you weren't trying?
>
> A: *Yes, that was one of the big things. (Patient Interview #1).*

Only one patient interviewed for the study portrayed family member behavior associated with targeting the patient in more positive terms:

> *If you think you are being forced to eat, it's not because they [your family] are mean. Its because they love you, that's what my mother did and it was a lot easier...they weren't trying to run my life. (Patient Interview #2).*

A second consequence of family behavior related to targeting the patient was that of patient withdrawal. Both family members and health care providers noted that patients sometimes used the strategies of pretending to be sleeping, and/or ignoring family members who were constantly fussing at them to eat:

> *We used to try and encourage him to eat, and we'd say, "well they'll put you back on IV again [if you don't eat], and he would ignore us. (Bereaved Family Member Interview #3).*

> *It's hard to know whether that's people's low energy or whether they just sort of tune out a little bit whether that's just disengaging or whether it's a means of, the only means they have left of, exerting some control. It the midst of this awful situation of dying, and especially if people aren't able to talk about it very openly, its, for them to say "Don't smother me, don't push all this food down my throat, I don't need it right now." So maybe it's a way of doing that is to passively withdraw and pretend you're sleeping. I'm sure that happens a lot. (Health Care Provider Interview #7).*

A third consequence of behavior related to targeting the patient was that of the patient trying to protect the family member. Even though patients did not want to eat, and eating had negative consequences for them in that they might feel nauseated and vomit, staff reported that patients would sometimes make a concerted effort to eat when the family was present. Health care provider data indicated that patients sometimes made a special effort to keep eating because they recognized that their family member wasn't ready to "let go" yet:

> *There was this one particular situation. There was this woman who would eat her lunch, in order to please her husband. And he would be leaving to go, and he hadn't reached the elevator yet and she was throwing it all back up. And this went on for a long time. And she told us, 'I have to keep eating for him. He isn't ready yet." (Health Care Provider Interview #9).*

> Q: Have you ever seen patients, where they eat until they are sick?
>
> *A: Yes. It will just sort of... a comment will come up about, that I'm eating just for her...(Health Care Provider Interview #10).*

A fourth consequence that had the potential to arise as a result of family behavior that targeted the patient concerned patient safety, specifically the danger of aspiration and choking that could occur when family members were overly zealous in feeding. Aspiration was of particular concern in unresponsive patients who lacked a protective gag reflex. This issue was identified by both family members and health care providers:

> *I remember one time when I was feeding him and every time I gave him a little spoon he was coughing. And I went and asked the nurse and asked if I should be giving it to him and she said no, because it is going to go into his lung, and he is going to be worse. (Bereaved Family Member Interview #2).*
>
> *"...by the time I came back to work the patient had died over the weekend and she was pretty poor. We were worried about how much the daughter was feeding her with the Boost, and the little bit of humor from the staff was that she probably "boosted" her Mom right out of this life and she may have. She may have given her so much that she ended up filling [the patient's] lungs."(Health Care Provider Interview #7).*

While it was important that families receive such information, health care providers cautioned that it was also important that the family not be made to feel "responsible" in the event that the patient developed pneumonia–a common occurrence in end stage patients irrespective of whether the patient had aspirated or not:

> *If anything, they kind of feel guilty about the fact that they have been doing it and maybe making them worse. Its kind of, you have to be careful that you don't make them feel worse. I don't like it when someone is being fed inappropriately. I am just careful about that they don't do that because our patients will get pneumonia, and so if the family is told that twenty times over, and the patient does get pneumonia, they think, "Oh, I killed them!" We have seen that where the spouse has killed them because they have fed them....The problem is, they are going to get pneumonia anyway...(Health Care Provider Interview #10).*

When staff witnessed behavior by families that they believed put the patient at risk, their responsive action was that of providing the family with information about the burdens and benefits of that particular course of action. As such, the consequences of targeting the patient, that is, the provision of information or teaching by health care providers, subsequently became an intervening factor in the model of "doing what's best". Indeed, the provision of information to families by health care providers about a range of issues constituted an important intervening factor in this study, and will be discussed in greater detail in the section of the dissertation examining such factors.

Not being able to get calories in through the use of the strategies associated with fighting back also had consequences for family members. When family members were not able to get calories in by targeting the patient they reported feeling anxious, frustrated incompetent, guilty, and rejected:

> *I feel guilty if she doesn't eat. It's that feeling that you think any nourishment will help. It's like when you have a baby and you are always feeding it and giving it as much as you can. If Mom hasn't had enough, you try and give her more. (Family Member Interview #2).*

Such feelings were familiar ones as they had also been experienced at home, prior to admission, when efforts to increase intake had failed:

> *... I used to think I was a good cook. It makes me feel awful. It makes me feel like I am good for nothing. (Family Member Interview #1).*
>
> *Well, it was very frustrating. I was at my wits end to try to invent or to try to come up with some recipes that would appeal to him. It was difficult. It really was. It was like an ordeal.... (Bereaved Family Member Interview #10).*

Health care providers were acutely aware of family members' frustration and feelings of helplessness in this regard:

> *Probably the biggest factor is the helplessness of this deal that they have to sit down and watch somebody fade away and die. To them, nutrition and fluids is very kind of instinctive to do. If you take that away from them, and they can do nothing but just sit and watch their person die...part of it, there is a concept of passivity of letting someone die and if they don't sort of fight they feel they are letting that person down. (Health Care Provider Interview #10).*

However, despite these feelings, the goal of getting calories in remained paramount for many family members, as to fail at this goal had unthinkable consequences:

> *At the same time, I couldn't get discouraged because we knew we had to make her eat. We had to make her eat because she had to fight, and the only way to fight was by eating, and to fight the cancer was to eat. (Family Member Interview #4).*

Such consequences included the patient's wasting away:

> *We tried a lot of things but we didn't want to give up because you know they are losing nutrition and we didn't know how long he was going to live... so you didn't want him to be skin and bones so we would try anything... (Bereaved Family Member Interview #9).*

Families also expressed concern that patients who did not receive adequate food and fluid might experience uncomfortable, and/or hastened deaths:

> *I would see the IV as it would stop the person from being dehydrated and its also very good because other medications can be given at the same time and they don't have to swallow. It makes everything much easier. It makes the passing easier. (Bereaved Family Member Interview #8).*
>
> *Because you know, if you don't drink, you are going to get dehydrated and he never had any intravenous last time at the hospital. And I knew this would be a problem if you don't drink. How long could you live like that if you don't take nothing, unless they give you something by needle? I knew he wouldn't last too long...because the little bit he was having was never enough for a person to live on (Bereaved Family Interview #2).*

Families who believed that fighting back was the best approach took some solace in the fact that they had done all that they could, and that they hadn't abandoned the patient or given up. HCP's interviewed for this study understood this:

> *Explain to them why they can't eat, and if you have time, say they want pizza and get it and they only take one bite. At least they have tried it. This is a phase that will not last long. This isn't going to go on forever. In a week or two, he probably won't be asking for anything. Then you feel guilty, Why didn't I do more before, when he was eating. Maybe he will only have one or two bites, but at least you have tried.*
>
> Q: Its kind of preventing the regret and remorse that later on they may feel?.
> *Yeah, like I wish I had done this or that. (Health Care Provider #3).*

Though presumably designed to evoke a change of behavior on the part of health care providers, the accusatory stance associated with targeting the health care provider was rarely successful in enlisting the staff to "fight back" in ways the family envisioned. However, the strategy of targeting the health care provider did have certain outcomes or consequences. First, the targeting behaviors that involved blaming and accusing the health care provider of neglect served as a signal for the health care team that the family was struggling with a much larger issue-- the realization that their relative was going to die. Accusations of staff neglect regarding nutritional care were thus seen as a harbinger for a much larger, more complicated set of issues:

> *... there really is a lot more going on than just the food. A lot of it is guilt, like have you done something in the past that's why they are dying. You have to do something to makeup for the past. Lots of things come to us through food. Even like, if you feel kind of guilty about something, you buy something special for dinner that night. You use that as a way of smoothing things over. We do it a lot, and for ourselves, we use food to make us feel better. (Health Care Provider Interview #2).*
>
> *In my mind, nutritional issues are often a marker for another problem in palliative care and the disease process of our patients Often it opens an avenue on to issues on grief and denial and guilt by family members. You have to look further than just a simple question of nutritional issues. I think it is a major issue in palliative care. I think it is a harbinger for other things. (Health Care Provider Interview #4).*

Staff consistently indicated the importance of dealing with the anger that fueled accusations of neglect. Responses to the blaming pattern ranged from gentle reassurance that the patient was comfortable in the absence of minimal intake, to a more forceful denial of the accusation. In attempting to interrupt the family member's pattern of blaming, health care providers explained that they were trying to convey to the family that the staff was not "the enemy", and that the family and the staff were "all on the same side":

> *My initial response is, and that is sort of an accusation in a sense, and my initial response is to get back right away with the response that "Its not the lack of food, it's the disease and you know that"... Give it right back to them, we aren't killing them, the disease is and then explain the disease. It sounds cruel, but to me you have to go back to them with a shock and then go from there and explain the disease and what its doing and that works for me. You have to say, no. Its not the lack of food that's doing the damage. It's the disease that's doing it and so it's a slow process of going through and being very patient with them. (Health Care Provider Interview #3).*

Other ways of responding to family anger had to do with validating the feelings of anger that were being expressed. Listening carefully to what families had to say was important in being able to both fully understand the anger that was being experienced and prevent it from escalating:

> *I think the most important way of responding, the most important piece of it is acknowledgment. Right off the bat it's really to hear people and not...not sort of label people, or not to say, "They don't get it." Hear what they are saying. The words they're saying about the feeding issues. But hear what's behind the words too...Reach behind what you're seeing and recognize that there's more to it. Listen to people and let them know they are acknowledged because I think that's the most important piece of it all. If we sort of become defensive or we quickly extinguish their claim around food, it [the anger] just kind of escalates. If a person is heard though, that does...it's harder to escalate. (Health Care Provider Interview #9).*

Responding to and acknowledging anger was seen as a necessary first step in being able to explore family concerns about the patient's plan of care generally, and nutritional care in particular. Health care providers identified that it was important to respond to anger in order to be able to engage in teaching and collaborative goal setting with family members around all aspects of care–including nutrition:

> *So acknowledgment is the first thing. I think the second thing is information. And really to sit down and spend some time with people and really sort of talk to them about ... "Well, what do they think? What are they asking for? Find out what their goals are. Tell them what our goals are and make sure that our goals are all on the same wave length. And so.. So that we're working together ...you might be giving your best explanations and information but it's not totally registering. Because if you don't acknowledge the feeling that's coming at you, that person may not even be capable of getting the information (Health Care Provider Interview #9).*

Despite the intellectual realization that families lashed out because of their pain and distress, such interactions were still painful and discouraging for some of the health care providers interviewed for this study:

> *Its hard. Because the family distress is right there They're saying, "Oh my God", you know. I see him getting thinner and thinner. They're starving him to death...Uhm, and I...I feel awful inside of me–emotionally...(Health Care Provider Interview #11).*
>
> *...they [the family] were somehow at odds with what I considered good quality palliative care and symptom control and comfort care. They see it as you are no better than Jack Kevorkian by doing it this way [not aggressively feeding]. You have given 120% for this person and the amount of empathy and caring you have and I feel above and beyond what is expected and then you're met with that. (Health Care Provider Interview #4).*

However, it was clear that staff realized the importance of not taking the anger personally:

> *You just have to keep reinforcing and realizing that its not you they are angry at, it's the whole picture of things. They have to take it out on someone. (Health Care Provider Interview #5).*

> *Intellectually, you have to kind of pull back and say-"Well wait a second. We're not starving them at all. They have no appetite. Is it better to force feed them? You know, when they don't want to have that? That can be worse than not eating at all. (Health Care Provider Interview #11).*

Health care providers consistently indicated that while it was important to respond to family anger, is was equally important critical not to get "hooked" into it, as such reactions were futile:

> *There are times when people will push your buttons or will hook you in some way. You end up, the image that I use, rather than standing back and letting it go by and waiting for it to settle, you get sort of sucked right into it. And you just,..you just spin around with them. And then we spin around with each other. And then we, kind of...go right through the roof. (Health Care Provider Interview #9).*

In the course of responding to family anger, health care providers were able to begin to elicit and clarify patient and family perspectives regarding the goals of care generally, and nutritional care specifically. Eliciting the goals of care provided a vantage point from which to begin to understand family member expectations, and provided health care providers with direction regarding some of the educational and psychosocial issues that needed to be addressed:

> *What are the hopes or goals for this person? So I would want them to tell me what their concerns were. What their hopes or goals were and what way they were going to do it. If they seem quite not likely achievable then I would explain that and why and based on what kind of evidence that we have. Often that's enough.....(Health Care Provider Interview #10).*

> *...Often I ask the family what are the goals and sort of spell those out and often if they are giving me the objective guide lines, like I want my wife to live as long as possible. I'm not comfortable to let her starve to death. I don't want her to suffer...... It's a good avenue, an inroad to start in dealing with an issue (Health Care Provider Interview #4).*

Health care providers also stressed the importance of clarifying specific goals or outcomes for the patient *prior to* the implementation of such interventions such as IV hydration or nutritional support such as tube-feeding. The identification of clear outcome criteria provided critical indicators for family members and health care providers in evaluating the patient's response to the intervention:

> *... there is an element of trial where there is some kind of feeding apparatus but again, when you are interviewing and you question the situation you have to have very clear goals in your mind and a plan and you evaluate it and then you start... (Health Care Provider Interview #10).*

While responding to anger, providing information, and engaging in collaborative goal setting with the patient and family were seen as the ideal pattern of interaction, such behaviors did not always occur in practice, and indeed had consequences of their own for the palliative care team. Health care providers in this study indicated that it was not helpful when colleagues were either too rigid and dogmatic when dealing with families, or too laissez-faire, as neither approach was seen as helpful in trying to address underlying issues:

> *Sometimes it might become a territorial issue... And you can see someone take a very firm stand. Well this is not needed at all. It's sticking to your guns sort of thing. That's one sort of inappropriate response that can be defensive. Another one is just the opposite. Just sort of saying, "Oh well, I mean if they want it, just go ahead." And that kind of passivity can be, I think, can be damaging too. It's not like the family necessarily wants you just to agree with them. Although maybe they do at one level, but at another level there's often unresolved stuff or things that are stimulating the question (Health Care Provider Interview #9).*

Some staff members were distressed when they perceived that nutritional interventions were initiated in order to "satisfy" a demanding relative. For example, this informant identified a situation that she described as disturbing because she felt the intervention that had been ordered was not in the patient's best interest, but instituted to placate a demanding relative :

> *... he was hemorrhaging profusely from his mouth, from his nostrils around the tongue... you could actually see the tumor and he was bleeding from that and he was bleeding through the trach after we suctioned all the blood away....and she wanted a tube feed. And the man is actually hemorrhaging right now, and said to her, you know, he's dying on top of what is happening it's not going to help him any more He's not hungry... and she said I cannot live with myself if he died. And I said to hold food, I could not live if I said that and he died. I know he's dying but I could not live like that if I said to you, hold his food. So I told her that I cannot live with myself if I give him tube feedings, because I know it's going to hurt him..(Health Care Provider Interview #2).*
>
> *Sometimes I feel frustrated because maybe you feel that the physician should be a little more firm in instructing the family but sometimes the family only hear what they want to hear too. They sort of get blinders on and they don't hear anything. (Health Care Provider Interview #5).*

The support of other members of the interdisciplinary team was identified as an important support mechanism when difficult issues concerning nutrition and hydration arose:

> *... it does a lot of good to be able to speak about it to people who can understand where you are coming from so I think team rounds and bereavement rounds if we are able to do it weekly or bi-weekly and just to run it by a colleague of yours. It is so very important for self care. Its not just learning [from] past mistakes, it sort of brings you closer for past difficult cases and it gives you sort of support in a sense for ongoing difficult issues in cases as well. (Health Care Provider Interview #4).*
>
> *Its very nice to have them there....when the emotions are getting thick...My training is this, your training is this, right? We, its kind of like a Venn diagram, there's a little bit of intersection in there...but your focus is a little different than mine. So you're better at that. (Health Care Provider Interview #11).*

A second consequence of family members targeting of health care providers was that it stimulated palliative care staff to engage in teaching with the family. This again is an example of the consequences of a strategy becoming an intervening factor in another part of the model of "doing what's best". This teaching frequently involved:

i) discussions around the etiology of the patient's weight loss and lack of appetite;

ii) explanations about what is "normal" and "expected" with respect to eating and drinking as the patient approaches death; and c) a delineation of the burdens and benefits of such interventions as aggressive oral feeding, TPN, and IV therapy. These aspects of teaching will be discussed in greater detail in Chapter IX of the dissertation wherein intervening factors are examined.

Taken as a whole, the strategies associated with fighting back seemed to be approaches that afforded family members some measure of control when things felt patently out of control. The notion of control as it relates to a fixation on food and getting her dying relative to eat is evoked in the comments of this daughter whose mother died of bowel cancer:

> *I really did fuss with the food issue and it wasn't that I didn't trust them [the staff] it was more control, It was a thing that I could control. It was the one thing I could say that wasn't being done. Yeah, I could intervene. It was a power thing. I was aware of the power in me, but I was also aware that it was something I could do for her. It was a way of seeing that things were done for her. (Bereaved Family Interview #2).*

Summary

This chapter has examined the "fighting back" sub-process of doing what's best. The main conceptual category related to this sub-process, that of getting calories into the patient, was discussed with respect to its associated behaviors and actions, and their resultant consequences. The next chapter will examine the sub-process of "letting nature take its course."

CHAPTER SEVEN:

THE SUB-PROCESS OF "LETTING NATURE TAKE ITS COURSE"

In contrast to families who were "fighting back", families who were "letting nature take its course" engaged in activities designed to care for the patient in which food and fluid played a nominal or negligible role. The main strategy used by family members who were letting nature take its course was captured under the conceptual category, "finding other ways to care". The sub-process of "letting nature take its course", its associated strategies, and the consequences of those strategies are schematically represented in Figure 3 below.

Figure 3

Letting Nature Take It's Course

Main Conceptual Category: *Finding Other Ways to Care*

Associated Strategies

Participating in Physical Care	***Being There***	***Protecting***
• bathing • oral care ▸ repositioning ▸ ambulating ▸ assisting staff	◆ linking with the outside world ◆ engaging in activities of living vs. dying ◆ physically touching	★ giving permission not to eat ★ shielding from others exerting pressure to eat and drink ★ shielding from the potential reactions of others in response to altered body image

Figure 3 (Continued)

Consequences of Finding Other Ways to Care for Family Members

➔decreased feelings of frustration at not being able to get the patient to eat

➔decreased time and energy spent in vigilant surveillance of patient intake

➔increased attention directed toward self-care activities

➔feelings of relief that patient would not have to endure potentially burdensome nutritional interventions

➔feelings of satisfaction that the patient's wishes regarding a non-aggressive stance related to nutritional care had been honored

Consequences of Finding Other Ways to Care for Patients

➔decreased agitation and distress as a result of not being barraged regarding intake

Family members who were "finding other ways to care" had shifted their time, energy, and focus away from trying to get the patient to eat, to other nurturing activities. This does not imply that they stopped asking patients if they were hungry or thirsty, or refrained from assisting them to eat and drink. Family members would still attend to these needs, however the activity around nutrition was now patient driven. That is, the desires of the patient regarding food and fluid intake now assumed paramountcy. This shift in orientation was accompanied by a harmonizing of family member goals with a realistic appraisal of being able to achieve those goals in light of the patient's declining condition. Such harmonizing or reconciliation is summed up well in the comments of this daughter who had moved from a fighting back posture, to that of letting nature take its course:

> *[I said to her] you eat what you can and if it's bothering you, then don't. I know I would offer it [fluid] to her but she wasn't responding to me, or anybody. This wasn't an issue. This was the end. (Bereaved Family Member Interview #1).*

Three main behaviors or actions related to the theme of "finding other ways to care" emerged from the data. They included: 1) participating in physical care; 2) being there; and 3) protecting.

1) Participating in Physical Care

Family members who were finding other ways to care frequently participated in the provision of the patient's physical care. The degree of participation was highly variable. For example, some family members who were quite comfortable with bathing and repositioning their relative would "dive in with both sleeves rolled up". Other family members, though not providing the care directly themselves, would willingly help the nurse or unit assistant with the provision of such care, and would offer to go and get extra towels, bed linens and miscellaneous supplies (e.g. Kleenex) from the large stainless steel supply cart that sat directly outside the medication room on the unit.

When interviewed about the types of care they provided, family members invariably mentioned the provision of oral care. The oral care described by family members consisted of cleaning the patient's mouth with a small disposable sponge with a handle dipped in water or mouthwash diluted with water, and the application of some type of lubricant to the patient's lips. This type of activity was typically carried out when patients were either too weak and debilitated to do it for themselves, or when they were unconscious. The activity of providing oral care appeared to hold particular importance to family members, and many of them equated this aspect of physical care with affording the patient much comfort. The comments of this bereaved family member were typical in that regard:

> *There were the swabs. We did that a lot...it kept her feeling comfortable. I don't think it particularly bothered her. It bothered her when you stuck something in her mouth if she didn't want it there (Bereaved Family Member Interview #1).*

When the patient's physical stamina allowed, participating in physical care also involved family members assisting patients to be up and about–whether that be through assisting them with ambulation, or taking them for a ride in a wheel chair. The weakness and debilitation of palliative cancer patients in conjunction with the need to ensure that all supporting technology "moved" with the patient posed significant "choreography" challenges for family members. The researcher was struck by the amount of knowledge family members required in order to participate in the patient's care in this regard. For example:

> *A patient with advanced metastatic breast disease and marked debilitation felt well enough to sit up in a wheel chair to go for a ride up and down the hall. The woman was a two-person transfer. She also had an IV in situ and a continuous infusion pump running, a naso-gastric tube in place that needed to be disconnected from the intermittent suction machine and the end plugged, nasal cannula for oxygen therapy that needed to be hooked up to a portable oxygen tank with wheels. Last but not least, she had a foley catheter in place that family members needed to remember to unhook from the side of the bed and hang on the side of the wheel chair, below the level of the bladder so that it could continue to drain by gravity. One family member pushed the wheel chair, one pushed the IV pole and infusion pump, and one struggled to push the portable oxygen tank that appeared to have one of those kind of wheels that you sometimes get on the shopping cart at Safeway that just won't turn properly, and make trying to push the cart a pain. It took well over 15 minutes to get the patient and equipment ready for the "outing". The patient was up in the chair for approximately 5 minutes, making one or two "trips" at most up and down the length of the unit, needing to return to bed because of increasing pain and nausea. (Field Notes, June 18, 1997).*

2). Being There

The second main strategy used by family members who were letting nature take its course was that of "being there". It may be argued that family members who were fighting back were also "there", that is present on the unit and with the patient. However, for family members letting nature take its course, "being there" meant something above and beyond being physically present. Being there seemed to involve honoring the patient, that is focusing on the patient as a person, instead of focusing on the disease. Invariably being there involved the use of touch:

> *I would want to be there for them in anyway I could. Holding their hand and talking to them. Just talking to them and being there for them, that is so important. I can't see them go without my being there, like for my husband, I had to be there. It was helpful for me. (Family Member Interview #5).*
>
> *...so I would just hold his hand, and if he wanted to talk, he would talk, but not force him. Just take their hand and not say a word. They get more out of it than becoming frustrated and agitated because we talk too much when we visit the person and after we leave they are exhausted. (Bereaved Family Member Interview #5).*

Being there seemed to be an important way for family members to communicate to the patient that they would not be abandoned:

> *Just being there all the time. I know when my husband passed away there was a young woman over there... and I feel so bad for her... The night my husband passed away, she said to my son, "your father has been very lucky to have someone beside him all the time"... She said she didn't have that chance to have somebody with her. And I think that's what it is for me... I think that's the best to give the most time you can give to them. I ... I'm so glad I did. And my kids they say, Ma, you did a good job. It was the last thing I could do, be there all the time. (Bereaved Family Member Interview #2).*

Being there also provided family members with the opportunity to talk to the patient about things other than their disease. Family members felt that it was important to keep their dying relative in touch with what was happening in the world outside the hospital walls:

> *Well, I would try to tell him what was going on, if I bumped into people who would ask about him....(Bereaved Family Member #3).*

A consistent feature of the activities associated with being there is that they tended to focus not on dying, but on living while dying. That is, many of the activities were those associated with normal day to day events, and were well described by this health care provider:

> *... if the person loves to hear someone read to them, or just be present. A lot of men really enjoy just having their wives sitting there, doing their knitting, or needle work or whatever. Just to be present. Just to sit and watch TV or whatever the person likes doing,*
>
> *whether to go for a stroll out in the hallway in their wheel chair or whatever... (Health Care Provider Interview #5).*

3) Protecting

A third strategy associated with finding other ways to care was that of protecting. Protecting refers to those behaviors by family members designed to shield the patient from physical or psychological danger, injury, or damage. First, family members would protect the patient from the negative physiological consequences of eating when they were nauseated and/or did not have an appetite. Unlike fighting back families who coaxed, begged, bargained with, berated, and force fed their relative, protecting involved counseling patients not to eat, or to take things slowly in that regard:

> *...I could see that he really didn't want it. I never forced him. If he couldn't eat, he couldn't. I'd say don't force yourself. I could see that he was chewing it and chewing it and it wouldn't go down. Even today, I don't push it. And he'd say I feel like we just had breakfast and here we are having lunch again and he would start to eat. I'd say, don't push it. (Bereaved Family Member Interview #10).*

Second, protecting involved protecting the patient from other family members who were pressuring them to eat. The data from this study indicates that there is variability within families about the extent to which individual members encourage nutritional intake in a dying relative. For example, this patient indicated that while her husband constantly encouraged her to eat, her adult children disagreed with his approach and attempted to protect her from his petitioning:

> *When Dad says, "Okay, eat this for me, you know. And you guys, you always tell him, "Leave Mom alone." (Patient Interview #11).*

In another example, a wife explained how she tried to protect her husband form the zealous feeding activity of her step-daughter; activity to which the wife was diametrically opposed:

> *His daughter came in November and she was forcing him to eat Jello, and I said he doesn't want it. Let him decide what he wants. She would say Dad, you've got to eat, You've got to eat. ... He would become agitated... He would say NO, and she would still say for him to eat to be strong. At the end, I was watching his two daughters trying to coax him and never giving up and I said, "Good Lord, leave the poor man alone!" (Bereaved Family Member Interview #5).*

Third, protecting involved family members being sensitive to the fact that decreased appetite and diminished pleasure related to eating and drinking constituted a significant loss for the patient. For example, the daughter of another patient indicated that she wanted to protect her mother from any feelings of loss that she might experience because she was no longer enjoying food as she once had. To that end, this daughter indicated that she preferred to "down-play" any discussion of food when visiting with her mother:

> *What I do is, I don't, even when she was more alert I would rarely, if I went out to eat somewhere, I would maybe just barely mention it or I wouldn't bring it up at all because I didn't want to make her feel ill at ease in case she was thinking about a time when she could eat more I played down anything food related on purpose. I don't make a big issue of it..I wouldn't want to go on and on about the fabulous meal I had knowing that her appetite has waned..I was sort of being sensitive about what maybe could be a touchy issue . (Family Member Interview #7).*

In a similar vein the daughter of another family member explained to the researcher how she had wanted to include her mother in a father's day "picnic" that their family was celebrating. The patient was experiencing a large bowel obstruction, was NPO (taking nothing by mouth) and had a naso-gastric tube inserted to help with intestinal decompression. Family members had brought lunch (i.e. the picnic) in to the hospital where they would gather as a family to eat and celebrate father's day together. The daughter was most concerned that the patient would not feel "apart of things" because she could not eat, and rather than exclude her from the family gathering, the daughter indicated that, although she knew that it might not be the most appropriate thing medically, she gave her mother "a few bites of a sandwich". She indicated she did so in order that her mother not feel left out *(Field Notes, June 20, 1998).*

While family members were concerned that not eating constituted an important loss for their relative, the majority of the patients interviewed for this study indicated that food simply no longer had any taste (*Patient Interview #8)*, or "tasted terrible" *(Patient Interview #11).* This may explain why loss of the pleasures associated with eating was not something that emerged from patient interview data. The only exception to this concerned a gentleman with an esophageal tumor who was receiving tube-feedings via a nasogastric tube. Though he was technically still taking in food, he nonetheless experienced the loss of the gustatory pleasures associated with eating:

> *He said first of all it was difficult for him because he missed the opportunity to be able to chew and swallow and enjoy food in the same way. I asked him now, does he feel hungry, does he have hunger pains the way he did before he was eating quite normally. He said no, he doesn't really feel full or empty but he knows he has to eat. He said he had a routine at 10am, 2pm, 6pm and 10 p.m. where he was ale to do the tube feeding procedure. I asked him if he felt he sort of missed the opportunities the same way in eating around the table with the family. He said, no, he said you just have to take things as they come and there is nothing else you can do about it. He said he understood that he needed to have this feeding tube because of his cancer of the larynx because he couldn't swallow. (Patient Interview #6).*

This particular patient had also discussed what it was like not to be able to eat as he once had, with other members of the health care team:

> *He would often say, I would kill for a piece of pizza right now", and I would say, "You still have the taste for it?", and he would say, "Oh, you know, I used to love pizza and a good steak and baked potato sounds good too." I felt bad for him because he would have loved something to eat...(Health Care Provider Interview #6).*

Some family members indicated that the loss of weight and change in appearance patients experienced as a part of their illness prompted requests from the patient not to allow others [friends, business associates, and sometimes other relatives] to see them in that way. Thus, a fourth type of protecting behavior that emerged related to family members protecting the patient from the reactions of others to the patient's cachectic appearance:

> *The only thing he asked me to do was he didn't want anyone to see him in the last stages... after they operated on him and he was bleeding and he couldn't eat and he was just skin and bones. And that was important to him. He was a very proud man and I didn't want to take that away from him.(Family Member Interview #5).*

Several of the patients in this study commented on the unintentional weight loss they experienced during the course of their illness. Early on in the illness trajectory, patients indicated that unintentional weight loss served as a signal that something was wrong, prior to the definitive cancer diagnosis being made:

> *The flu, I thought I had the flu. I thought I had it for about three weeks, and I decided it couldn't be the flu for that long because I was nauseated and losing weight....(Patient Interview #9).*

> *This is crazy because all my life I have tried to keep reasonably slim and now I am trying to put on weight, but I can't I thought there must be something wrong.(Patient Interview #8).*

Later on in the illness trajectory however, the issue of weight loss did not appear to figure prominently in the "big scheme of things" for most patients. Though they were aware that their wasted physical appearance may evoke a reaction in others, such reactions did not appear to be particularly upsetting for patients:

> *Oh yes, I have lost a lot of weight...about 95 pounds. I used to take a size 42 in slacks and now I take a size 12. But I don't worry about it. I have a lot of other things that I worry about more. Things like that are minor, as far as I'm concerned, what I look like. I'm sick. I'm in hospital. I've got a disease that's... I've got to worry about me and look after me , not about what other people think I look like. That's the least of my worries, what they think ... (Patient Interview #9).*

However, two of the patients interviewed in this study seemed to be both troubled by their change in body image, and and angered at the reaction their friends and family members had in response to their weight loss and subsequent change in physical appearance. One of the patients interviewed expressed her feelings in this way:

> *I have lost about 40 pounds. ..my clothes don't fit. ...if they don't like the way I look, that's too bad... I know a lot of people will come up and say, "I would never have known you. They say, but I don't pay no attention to them because if they don't want to come then they don't want to come. Simple as that. I have seen lots of my friends in this predicament and I wouldn't get all in a tizzy about it. You know, if a person hasn't been well for a year and half they aren't going to look like they did a year ago. Anyone who thinks like that, they better start on the other end of the chart. Its ridiculous. You can't look the same as you did, there is no way.(Patient Interview #8).*

That some patients were troubled by their unintentional weight loss and change in appearance was also supported in interviews with family members and health care providers:

> *It was her 75th birthday... There was about a dozen of us there and my daughter took several pictures ... and after my daughter took the pictures over to her, there was one picture taken with my little granddaughter and she tore the pictures up. And we asked her why she did that and she said that she just looked so awful cause she used to have a fairly nice complexion with a full face and when she lost weight, there was one picture of my granddaughter and her with their arms around each other. And we put it in a frame and when we took it over to her, she put it in the spare room behind a lamp, way in the back, because she said she didn't like the way she looked. So it bothers her. (Family Member Interview #8).*

> *Some people will say–No–I can't be seen. They'll limit their friends. Only certain people can see them as well. I remember a young patient who was having a great deal of difficulty with–17, he's the youngest kid that I've seen in palliative care. Extremely wasted. He was essentially...he really looked like a Holocaust victim. And his own sense of body image–I mean when you're 17...And his friends all wanted to see him but he..I don't know, it...it was just tough. (Health Care Provider Interview #11).*

Ironically, one patient indicated that she rather enjoyed the weight loss she experienced in the advanced phase of her illness, as she had been heavy all of her life:

> Q: Have you lost a lot of weight with your illness?
>
> *A: 80 pounds.*
>
> Q: How did you feel about that loss of weight?
>
> *A: Oh, I was happy with that.*
>
> Q: That was a good thing that happened?
>
> *A: Yeah. I always wanted to be a..Ah..Oh, you know you have this little small person inside you screaming to get out, right? And, ah...but I didn't want it this way for sure. But any ways, that's the way it is. (Patient Interview #11).*

Consequences of Letting Nature Take Its Course

There were several consequences associated with the strategies and behaviors used by family members who were letting nature take its course. First, family members indicated that they experienced a marked decrease in their frustration level once they had made the decision not to push the patient to eat or drink:

> *Yes, [I had] concern that he wasn't eating very much, frustration, but once I had decided that he was doing this his way, then it just lifted the weight...That was what he wanted to do, I know his Mom and Dad had both been, his mother was in a nursing home for years, his Dad had various strokes and was an invalid for a long time...I know my husband often said he didn't want to hang around like his Mom did, he didn't want to be a burden on the family. (Bereaved Family Member Interview #3).*

Moreover, they felt some sense of relief at not having to be ever present on the unit to monitor intake and audit the patient's care. There was a marked reduction in the vigilant surveillance activity that had once been so pervasive:

> *I try to be here. Not so much anymore. Before we had to be here. Now that she eats only what she wants anyway, we don't need to be here for meals. Just be here other times. (Family Member Interview #6).*

That family members experience some sense of relief when they stopped fighting and let nature take its course was expressed also by health care providers:

> *I think when you're loved one isn't able to eat or drink anymore for some families there's a shift and they start to see that this is the beginning of the end and sometimes they might not be able to admit it at that point, but they start to feel relieved that maybe the ordeal is over for their loved one at that point and maybe that's why some of the aren't pushing for IV or fluids at that time. They are starting to accept that this is coming to an end. My loved one is dying. (Health Care Provider Interview #7).*

Second, making the decision not to fight back enabled some family members to start focusing on their own needs, and taking care of themselves, particularly as it related to their own nutritional intake:

> *After that little while of frustration, thinking of only him I thought to myself just go ahead and make what you want. If he didn't like something and didn't eat it then so be it. And then I didn't go through all this frustration...even if he only ate a little bit of what I cooked, I had a reasonably decent meal. (Family Member Interview #10).*

The majority of family members interviewed reported that they had markedly altered their own eating habits when the patient was at home, prior to admission. Families indicated that the cooking odors associated with food preparation were a significant source of tension and conflict in the home, as they caused patients to feel sick or actually become ill.

A third consequence of letting nature take its course had to do with the comfort and satisfaction of respecting patients' wishes. For example, this widow explained to the researcher that accepting her husband's assertions that he was not hungry and did not want to eat helped to alleviate some of the frustration and guilt she experienced around his decreased intake:

> *I don't think we did the wrong thing. I'm inclined to let them do what they want. If it perks them up to bring something in from home to eat, fine. And if they have no interest, then don't feel guilty. (Bereaved Family Member Interview #3).*

A fourth consequence of "letting nature take its course" was that of decreased patient agitation and distress. Family members who were letting nature take its course felt strongly that pushing patients to eat when they clearly did not want to had deleterious results. Interventions were seen as being burdensome, inflicting unnecessary suffering, and prolonging dying. Said one family member:

> *I think to force a person who is sick [to eat], I think it's terrible.*
> Q: Say more about that. You think its terrible because...
> *They don't want it. They get frustrated. They get nervous, they get agitated....(Bereaved Family Member Interview #5).*

Another family member stated:

> *I just sort of thought about it. Getting in that one or two extra spoonfuls down would get her so agitated.... She has enough problems. (Family Member Interview #2).*

Patients appeared to appreciate not being harassed to eat, and not being made to feel like they weren't trying:

> *...they didn't bug me about it, if I didn't eat it then it was okay with them. They made it and if I didn't eat it well, there was no issue over it. It wasn't an issue. She understood that I might have felt like it when I was talking to her but an hour and a half later, I didn't want it. She understood that. (Patient Interview #9).*

One patient who had been gone out of the hospital for a few hours on a pass for the Thanksgiving holiday said this about her family member's non-judgmental response to her decreased appetite and intake:

> *My niece came over, it was Thanksgiving, and she cooked a little chicken and we had new carrots and we had cranberries and potatoes, but when it came time to eat it, I don't think I have any more than a few teaspoons and she didn't make any issue out of it. She put it all in little dishes and put it in the fridge and just said, you want any of it, it's there, and if not in a few days, get rid of it. Don't keep it too long. She didn't get excited over it, or bawl me out and say, "I've cooked all that for you, and went to all that trouble for you. She never said a word, not a word. (Patient Interview #9).*

Summary

This chapter has examined the "letting nature take its course" sub-process of doing what's best. The main conceptual category related to this sub-process was discussed with respect to its associated behaviors and actions, and their resultant consequences. The next chapter will examine the sub-process of " pseudo-surrendering."

CHAPTER EIGHT:

THE SUB-PROCESS OF "PSEUDO-SURRENDERING"

Somewhere between the sub-processes of fighting back and letting nature take its course lies a place of uncertainty for family members who are struggling to make a determination about just exactly what the best thing to do is. This sub-process of doing what's best is known as pseudo-surrendering. Families who were pseudo-surrendering were at once both trying to fight back, while at the same time trying to let nature take its course. The conceptual category that appeared to best capture and explain the strategies associated with the pseudo-surrender phase behaviors was that of "holding on while letting go." The sub-process of "pseudo-surrendering", its associated strategies, and the consequences of those strategies are schematically represented in Figure 4 below.

Figure 4

Pseudo Surrendering

Main Conceptual Category: *Holding on While Letting Go*

Associated Strategies	
Cognitive Waffling	***Behavioral Waffling***
☐ contradictory sentiments that reflected both a "fighting back" and letting nature take it's course approach	☐ contradictory behaviors that reflected both a "fighting back and letting nature take it's course" approach

Consequences of "Holding on While Letting Go" for Family Members:

→taking of a definitive stance regarding response to declining intake avoided

→increased feelings of helplessness and uncertainty

Consequences of "Holding on While Letting Go" for Health Care Providers:

→exploration of family goals and expectations

→initiation of teaching

→helping family to articulate what patient wishes around issues of nutritional care would be, were he/she able to make those wishes known

The two main behaviors or actions inherent in "holding on while letting go" were cognitive waffling behavioral waffling.

i) Cognitive waffling refers to the thought processes of family members as they struggled with trying to come to a decision about how best to balance the means and goals of nutritional care with respect to their dying relative. Waffling in this instance refers to a situation in which family members simply do not know what to do (i.e. they don't know what's best), and they waffle back and forth between thinking that fighting back is best to thinking letting nature take its course is preferable. The sentiment "yes, but..." was frequently expressed by family members who were cognitively waffling. That is, when talking about their behaviors related to nutritional care, they would justify one of the sub-processes of doing what's best, but then negate it in favor of the other sub-process. The following exemplars illustrate this point:

> *We would just say that you would get very weak if you don't eat more than a teaspoon at a time and he would say it just won't stay down. I knew that he was terminal, but...as soon as someone had a different idea [about how we could get him to eat], I'd say, why not let's try that! (Family Interview #9).*

> *"The main thing is that they are not starving to death and their stomachs are shrinking already so that they would be unable to have a big meal, even if they could eat it any way.....so forcing her or enticing her or cajoling her into eating when she was nauseous wouldn't accomplish anything, but, I think the only thing that created tension, if you could call it that, and it really wasn't, was that we would ask her if there was anything we could get for her. Anything else that she would like to eat. (Bereaved Family Interview #8).*

Family members committed to either fighting back or letting nature take its course, had clear convictions about the burdens and benefits of their particular course of action. In contrast, family members who were pseudo-surrendering seemed to be tentative and uncertain about the value of particular interventions. In the exemplar below, a family member expresses contradictory thoughts about the benefits of intravenous therapy:

> *You have to get a little something into their stomach. That's the only thing I would say, and you could give them something through an intravenous.*
>
> Q: So when you think of an intravenous, is that sort of like a replacement for food?
>
> *Uhm, I don't know, because I really don't know what they put in there. I don't understand what they put in there any ways. Well, I guess, if that..if that is the only way they can eat, the only way you can feed them then they have to have it. But I don't know what, I have no idea, what,.... It must be good because if it wasn't good, people wouldn't get it, right? To me it looks like a whole bunch of water. (Bereaved Family Interview #9).*

ii) <u>Behavioral waffling</u> refers to family members engaging in seemingly contradictory behaviors related to nutritional care. As such, behavioral waffling represented the operationalization of cognitive waffling. Family members who were engaged in behavioral waffling were characterized by health care providers as acting inconsistently toward the patient with respect to nutritional care. That is, family members would, for a time, be engaged in behaviors congruent with that of letting nature take its course. However, such behaviors were not sustained, and were often quickly replaced with behaviors more consistent with the sub-process of fighting back. In the exemplar below, a health care provider recounts how family members who are seemingly content with finding other ways to care (e.g. participating in the physical care of the patient) can quickly flip over into behaviors associated with targeting health care providers–a behavior associated with that of fighting back:

> *They feel involved with the care but that might only last for that period and then another person might walk in on that shift and they'll say the same thing, "I think he's thirsty. Those are the questions again, Did he eat any breakfast?"....Are we going to feed him?"...(Health Care Provider Interview #2).*

Consequences of Pseudo-Surrendering

Several consequences were associated with pseudo-surrendering. First, adopting a pseudo-surrender stance technically provided family members with a way to avoid committing themselves to a definitive course of action where the patient's nutritional care was concerned. Ironically, however, the avoidance of this commitment did not appear to be associated with a concomitant degree of emotional relief or peace about the issue of nutritional care for their dying relative. Indeed, feelings of helplessness and uncertainty appeared to plague family members who were waffling. These feelings are captured well in the comments of this bereaved family member whose sister died of breast cancer:

> *You're helpless to know what to do. If there was something that we could do to make it easier. I think that is the way everybody feels. If you know what to do, you do it, but none of us really knew what to do. (Bereaved Family Member Interview #8).*

Second, the behavioral waffling of family members sometimes had less than desirable consequences for the patient. This health care provider recounts the example of a man whose wife was dying of lung cancer. The husband had been struggling with not feeding his wife, and had been taught about the potential danger of doing so, as the patient was unresponsive and did not have a protective gag reflex. The health care provider explained that the patient's husband appeared to understand this, and, for a time, did not engage in any feeding behavior. However, he was unable to sustain this behavior change, as the following exemplar illustrates:

> *There was a woman who was in her 50's but she deteriorated quickly and she was choking and I said to her husband, it's best not to give her food...and I thought I had explained it to him ... but later he came running down the hall and he said she was aspirating and choking. He had given her food, he wanted to make sure she had water and she was choking to death. (Health Care Provider Interview #3).*

Third, when health care providers detected waffling behavior in family members, they engaged in strategies specifically designed to help families make more definitive decisions about the patient's plan of care. When family members were not sure what to do, and/or when the patient's wishes were not clear on the matter, health care providers would encourage the family member to make decisions based on what they thought the patient would want if he or she were able to make their wishes known. This approach both gave voice and credence to the patient's wishes, and helped to absolve family members of feelings of guilt and regret around making the "wrong decision":

> *..if your loved one when he or she was well could look at him or herself and could say, "if I ever get to that state this is what I would want to do" what would they say? That's just another strategy because then the family member doesn't say do this, do that, its not their responsibility they are just being the voice of their loved one and most often they know very clearly... Its about giving the family members the chance to be the voice of the patient to absolve them from any guilt and decision. (Health Care Provider Interview #7).*

Health care providers were aware that although such decisions were designed to absolve family members from feeling guilty, they were still difficult to make. Thus, family members were encouraged to take their time in making such decisions:

> *...think about it and we would say you don't have to decide how so there wasn't ever the pressure that you had don't decide right now. You take your time... (Health Care Provider Interview #8).*

Pseudo-Surrendering and the Issue of Conceptual Density

The researcher is aware that the sub-process of pseudo-surrendering is not as conceptually dense and complete as the sub-processes of "fighting back" and "letting nature take its course." Initially, data related to the sub-process of "pseudo-surrendering" was thought to be something idiosyncratic to the occasional family member, because it did not emerge repeatedly in any of the data sets coming from patients, families or health care providers. However, over time, it became clearer that the waffling behavior inherent in pseudo-surrendering although not an everyday occurrence, was a feature associated with family member behavior as it relates to nutritional care of the dying.

Confirmation that the pseudo-surrendering sub-process is an important aspect in understanding family behavior was obtained in large part from health care providers who witness such behavior, and three family members in this study who concurred that they had engaged in waffling behavior indicative of pseudo-surrendering. Therefore, the researcher deemed that although the conceptual category underpinning pseudo-surrendering (i.e. holding on while letting go) was probably not fully saturated, it nonetheless constituted an important part of the nutritional care experience and as such needed to be reflected in the model emerging from the study. Future work aimed at more fully exploring the dimensions of this sub-process is warranted. For example, following family members longitudinally during the terminal phase of the cancer trajectory may enable researchers to more fully capture, track, and describe the salient indicators of pseudo-surrendering.

Summary

This chapter has examined the "pseudo-surrendering" sub-process of doing what's best. The main conceptual category related to this phase, holding on while letting go, was discussed with respect to its associated behaviors and actions, and their resultant consequences. The next chapter describes the intervening factors that served to facilitate and/or constrain the behaviors associated with each of the model's sub-processes.

CHAPTER NINE:

INTERVENING FACTORS

Introduction

In grounded theory research, intervening factors are those factors that act to facilitate or constrain the use of certain strategies (Strauss and Corbin, 1990). In this study, seven factors were identified that appeared to influence the extent to which family members enacted the strategies associated with fighting back, pseudo-surrender, and letting nature take its course, and might move back and forth between these sub-processes. These factors included: 1) family members' perceptions regarding the cause of the patient's decreased intake and declining status; 2) family members' perceptions about the nature of palliative care 3) family members' appraisal of the burdens and benefits of nutritional interventions; 4) information; 5) experience; 6) readiness to let go of the dying individual; and 7) the symbolic meaning of food.

1) Perceived Cause of Decreased Intake and Declining Health Status

An important intervening condition influencing the strategies used by family members in this study related to their attribution concerning the factor(s) causing or contributing to the patient's declining intake of food and fluid. Four categories of factors were identified by families in this study as having a negative impact on the patients' nutritional status. These categories included disease-related factors, treatment-related factors, care environment related factors and patient-related factors.

Disease-related factors consisted primarily of symptoms that patients experienced in response to the type and location of their tumor(s), and included such things as: a) dry mouth *(Patient Interview #1)*; b) feeling full fast *(Patient Interviews #1&9)*; c) nausea *(Patient Interview #3)*; d) dyspnea *(Patient Interview #1)*; e) sore mouth *(Patient Interview #2)*; f) bowel obstruction *(Patient Interview #3)*; h) alterations in taste *(Patient Interview #3&9)*; i) fear of choking *(Patient Interview #6)*; j) pain *(Patient Interview #7)* and; l) the development of food aversions *(Patient Interview #8)*.

Treatment-related factors identified by family members as having a negative influence on nutritional intake primarily included the side-effects of medications and treatment used to manage symptoms:

> *They gave her three doses of Baclofen and it threw her for a loop, so she slept all day yesterday....I guess the medication acts differently on different people. So it happens that when she has bad days, she doesn't eat at all (Family Member Interview #2).*

> *She didn't want to come to the palliative care unit because all they do is pump you full of drugs and that's all they've done. She certainly doesn't want to eat or drink with all that medicine. (Family Interview #4).*

A contrary example to the negative side-effects associated with many medications and treatments was the appetite stimulating effects of steroids. Family members were particularly pleased by this effect:

> *I think it was Prednisone...But whatever it was, it increased his appetite so much that he was gaining weight by leaps and bounds...and he was just gaining a lot because he was constantly eating....it was almost unreal (Family Member Interview #10).*

In contrast, this young female patient who was prescribed Prednisone lamented about her unwanted weight gain:

> *The steroids make you eat, and make you into an energizer bunny. I have a really good appetite. I have never eaten so much in my life. They are taking me down off the steroids slowly thank God. They were making me really fat. I went from 126 to*

> *190 pounds. I have never had such a bad body image in my whole life. Poundage, mega pounds. (Patient Interview #2).*

Factors related to the care environment that contributed to intake difficulties, albeit to a somewhat lesser extent than disease and treatment related factors, included meals being scheduled too closely together:

> *My daughter phoned and said he just had breakfast, it was late. It was 10:00 and then they bring lunch at 12:00 and he can't eat lunch when breakfast was so late. (Family Member Interview #6).*

> *"... and because of the inconsistencies of time many will not be too pleased to get lunch so quickly after breakfast and some will say "Oh thank you" and my favorite response is, "don't thank me until you have seen it!"... (Health Care Provider Interview #8).*

The poor quality of hospital food served was also implicated by family members as contributing to decreased intake:

> *"...but they seem to put a lot of cabbage in the soup and its gassy and tomatoes seem to bother her like today, she had minestrone soup and after a couple of pieces of tomato she felt nauseated and she couldn't eat anymore. (Family Member Interview #8).*

Finally, inadequate numbers of staff available to feed patients who needed assistance were identified as having a negative impact on the nutritional care patients received. Like families, health care providers interviewed for this study also identified sub-optimal staffing levels as having the potential to contribute to problems related to patients' nutritional care:

> *We have less staff now too. We used to feed patients but now we have 3 nurses and you are doing a lot of medications now and you just don't have the time to sit and feed somebody. (Health Care Provider Interview #2).*

> *Mealtimes on the unit they are always a busy time...so if one of the nurses is tied up in rounds at lunch time and people are going off for lunch it has implications because then you have got three nursing assistants now too, so your staff is effectively cut in half. There are fewer people so if somebody is very ill and has other pressing needs or they need some medication for pain or symptom management they need some complex assessments at those times when feeding is going on. So they go low on the list of priorities. So yes, I think the staffing issues do make a difference. (Health Care Provider Interview #7).*

Both families who were "letting nature take its course" and "fighting back" noted that the three aforementioned factors had a negative impact on the patient's nutritional intake. However, family members who were fighting back, also implicated factors specific to the patient as playing a major role in nutritional difficulties. These patient-related factors refer to those attitudes held and actions taken (or not taken) by the patient that resulted in decreased consumption of food and fluid. This category of factors was described largely in terms of personality traits of the patient and included such things as the patient "being stubborn" or being a "picky eater":

> *And when I got to the end of the hall and I sat down and tried to encourage him to eat and he was almost pushing me away...and then he pushed his tray on the floor and I don't know. I think I realized then that he wasn't going to eat that much.*
>
> *Q:* What did you understand that to mean, when he did that?
>
> *I thought he did it on purpose. He didn't eat very much after that...I don't think it was really a reflection of the food or the staff, I think it was just his stubborn streak coming out. (Bereaved Family Member Interview #3).*
>
> *She is very rigid in her ways. She would only eat chicken legs with the thigh attached and it has to be that way. She is very rigid that way, and she is very stubborn. Like, coffee has to black, and that's that. (Family Member Interview #13).*

In addition to being a "picky eater", the theme of the patient "not trying"and/or "giving up" was also raised by family members when explaining reasons for problems with intake:

> *We thought maybe she's not eating on purpose. We thought maybe she just wants to give up.....(Family Member Interview #6).*
> *I said to him, J., if you want to get out of here, you have to try and eat. You're not giving it a good fight. But he said, "I'm tired"..and I kept telling him anything you undertook you always succeeded at, but I said, "You've got to fight". (Bereaved Family Member #5).*

Lack of effort, and failure to "fight" were also identified by this woman when asked by the researcher to explain why she believed her dying husband wasn't eating well:

> *He didn't persevere and try. He says he does, but I don't think so. He didn't want to eat and he was being that way. He used to come to the table and take one look at it and then put a face on. You know darn well that he wasn't going to eat it... I know he probably hasn't got long, but if he tried maybe he could fool them again.(Family Member Interview #1).*

Interestingly, one bereaved family member who did not ascribe personal responsibility to her own husband for not having a more robust appetite nevertheless readily hypothesized that a personality trait of vindictiveness might explain why some patients don't eat:

> *Is he trying to hurt them in someway? Is he angry because he realized his time is near and we are going on living without him? I mean was it those kind of things happening with him? You hear of patients coming in very bitter with their illness and they are almost angry with the family . There you are having a good time living, and here I am. (Bereaved Family Member Interview #10).*

Later in the same interview when asked how she would have explained her husband's actions if had been reluctant to eat, this widow also evoked the notion of "giving up":

> Q: What would it have felt like if he had said, I'm not hungry. I don't want to eat anything. Please don't feed me. I don't want anything.

> *A: That would have been quite bad. It would have given the sign that he was giving up and just wanting to slowly die away I guess (Bereaved Family Member Interview #10).*

That there are some people who fight, and some who give up was also expressed by this family member. The issue of effort, and the importance of dying patients having at least "tried to fight the good fight" is suggested here:

> *It never bothered me that she didn't finish her tray, because I knew she wouldn't starve herself. I watched my father-in-law intentionally cut himself off. And he was in palliative care as well. That was different...my mother was a fighter. My father-in-law wasn't. The day he heard he had cancer, he quit eating. That was it, whereas my mother fought every inch of the way. (Bereaved Family Member Interview #1).*

> *He wanted to try to eat because he didn't want to give up because if he didn't eat that was a sign that he was giving in, and he wanted to eat, so he'd try. I understood it was tough for him to eat....He tried. Even when I could see he really didn't want it. (Family Interview # 10).*

Interviews with health care providers support the finding that family members often include judgements about the extent to which the patient is attempting or making the effort to eat when discussing declining appetite:

> Q: Do you find that family members sometimes put the brunt of, or responsibility at the feet of the sick person. "If you really wanted to eat, you would. You're not trying."

> A: *Oh yeah. Like this husband said to me that, "Of course she's not eating and she's getting weaker and she's not eating." And then he ah...and then his rider was very quickly, "but she's trying." So, like that was very important for him to put that in. Yeah you see that all the time. (Health Care Provider Interview #9).*

Taken as a whole, the data suggested that to some extent, families both blamed patients for the nutritional difficulties they were experiencing, and held them responsible for remedying those difficulties:

> *...but some people will fight and other people will just give up and let themselves go. A lot of people beat it for a long time by being strong willed and saying, I'm not giving into it. ... [I said to him] if you want to get out of here, you have to try and eat. You're not giving it a good fight, but he said, "I'm tired"... I kept telling him, anything you undertook, you always succeeded, but I said "you've got to fight this battle ... "(Family Member Interview #1).*

Family members appealed to two main sources of evidence to support their contention that the patient should be held responsible for "underachieving" with respect to the amount of food and fluid they were ingesting. The first source of evidence concerned the patient's inconsistency with respect to appetite. Family members reported that patients would be able to eat fairly well at one meal, but then eat nothing at the next. This inconsistency frustrated and angered family members, and raised their index of suspicion about the veracity of patient claims that they had "no appetite" or "felt full" after only a few bites of food or sips of fluid:

> *I think she could drink more. She drinks coffee, but she drinks out of a china cup and there's not a lot in there. She doesn't drink as much as she could. (Family Member Interview #13).*

The second source of evidence advanced by family members was their observation that patients tended to eat more when they were "distracted" by the presence of others at meal times. Families reasoned that if the patient truly did not have an appetite, distraction maneuvers would be ineffective in promoting enhanced intake. The very fact that patients would eat if distracted strengthened family member assertions that the patient's appetite was under their conscious control, and served to further invalidate patient claims of anorexia:

> *He would eat better when the children, teenagers were around. Maybe it's a socializing thing. Maybe he didn't seem to notice how much he was eating. He ate better than when he was alone. Just the conversation would distract him from his mouth and he would eat better than if it was just the two of us. (Family Member Interview #8).*

> *... She picked at it [food] with other people. She never ate it alone from one day to another. You could see that it hadn't really been touched. But if someone was there to eat it with her, then she would... (Bereaved Family Member#1).*

For their part, all patients in this study readily acknowledged that they experienced a waxing and waning of appetite. Consonant with the descriptions provided by family members, patients explained that they would often have a craving for a particular type of food, only to find that they no longer desired it a few minutes later. One of the patients described her fleeting appetite this way:

> *My appetite is not good..... It's there and it's not there. Sometimes you feel like you want it, and then you don't want it. Some days you feel like, oh, I could sure eat that and when you go to eat it, its not what you want. (Patient Interview #9).*

> *I want it and then I get it and I'm like a little kid. Now I don't...you know, I'm not...not happy with it today. But for a while I was doing good. I was eating roast beef, eh, and roast chicken and... So I don't know. And then I think, oh, I'd like, uhm, something with some...like pop or something. And then I get it, and no. (Patient Interview #11).*

However, patients were quick to point out to the researcher that such waxing and waning was outside their conscious control, and not something that they did deliberately:

> *It's not that I don't want...it's not that I don't want to...it's not that I don't want to eat and get strength, its just that I don't have the...desire. (Patient Interview #11).*

Health care providers in this study acknowledged that the appetites of palliative cancer patients do typically wax and wane. However this phenomenon was attributed in large measure to the disease process generally, and the cancer anorexia-cachexia syndrome specifically. HCP's thus did not share family members' perceptions that patients failed to eat because of such characteristics as stubbornness or vindictiveness. Health care providers did express the belief that, in rare instances, some patients deliberately stopped eating and drinking in an attempt to try and hasten their own death:

> *"...I had an incident once when this fellow wasn't going to eat anymore, and he wanted to die and for several weeks, I'm sure for at least two weeks, he would be refusing his trays all the time...This particular evening he said, "tonight I'm going to take this tray", he says, "it has been two weeks I've tried it and it's not working"'. And I said, "what do you mean it's been two weeks? [He said], "well, I thought if I quit eating, I thought I'd die. Its not happening, so I may as well be eating!" (Health Care Provider Interview #5).*
>
> *I have seen patients that have stopped eating because they want this to end quicker. The suffering is too much, so if I eat less, maybe I'll die quicker... They want it to end quicker, so they stop eating. (Health Care Provider Interview #3).*

For health care providers, the waxing and waning of appetite was seen as part and parcel of the disease scenario, and was not parsed out as a behavior patients engage in due to quirks of personality:

> *... one day it might appeal, the next day it might not. Sometimes on the menu what they circle for the next day might sound good that day, but when it comes in the morning, they don't want it. So we try to compensate for that. We try by using a few things we have in the fridge. (Health Care Provider Interview #1).*
>
> *But this morning, when I brought in his tray, he says, can you open it for me. I'm hungry. I haven't heard him say that all week. Some days are good and some are bad. They seem to go through that (Health Care Provider Interview #6).*

"Letting nature take its course" families did not hold the patient responsible for his/her nutritional difficulties, and did not identify such patient-specific causes as being stubborn or giving up as contributing to the problem. Rather, they tended to frame difficulties with eating as a manifestation of the disease process, or secondary to troublesome symptoms associated with the disease:

> *If he ate or didn't eat, that wasn't the point. It was the illness that made him eat or not eat. (Family Member Interview #5).*
>
> *We witnessed her nauseousness often enough to know that this is not a put on thing. This is for real. (Bereaved Family Member Interview #8).*

2) Family Perceptions about the Nature of Palliative Care

Health care providers interviewed for this study felt that family behaviors associated with fighting back may be motivated by the misperceptions families hold concerning the amount and type of care that patients received once admitted to a palliative care unit. Palliative care staff asserted that families are often afraid that "nothing will be done" for their dying relative once they entered the hospital. This fear, at least in part, was believed to be a driving force behind accusations of substandard care, and requests for aggressive intervention related to nutrition:

> *Often they [families] think that in palliative care, we don't do anything...I don't want to come there because you don't do anything. We don't get IV's or whatever, all you do is sit and hold hands.. It's taken literally, we don't do anything. ...It is so literal. It is the same with the food issue. So, you get, "Can they have IV's there, or tube feeding there?" And I say yeah, we would do almost anything but is it appropriate? That's the issue, not whether or not do we do it here. (Health Care Provider Interview #3).*
>
> *I would say more they are asking for it [interventions around food and fluid]...because if you go there [Palliative Care Unit] they won't feed you. You won't get this, you won't get that. They just hold hands and they can't do any active intervention, so you could starve and be dehydrated and they just let you die. (Health Care Provider Interview #7).*

A consistent sentiment from health care providers was that a variety of interventions were available to patients, and, if appropriate would be instituted. It was clear that the palliative care staff interviewed for this study did not delivery care according to some sort of blanket policy. Rather, each case was taken individually and followed carefully over time in order to determine what the most appropriate course of action might be:

> *Certainly families were scared to go there [PCU] in a sense because they had the impression that we wouldn't do this in palliative care and we wouldn't do that in palliative care and the bottom line is that I believe palliative care is not procedure specific in what we do and what we don't do. I think it is more goal specific and you have to have open minds and explore all avenues. Once we get past that philosophy that palliative care is treatment specific and change it to goal specific we will have less of a problem. (Health Care Provider Interview #4).*

3) Perceptions of Benefits and Burdens of Interventions

The extent to which family members tended to fight back versus letting nature take its course was also influenced by their perceptions of the burdens and benefits of interventions designed to support and augment the nutrition and hydration status of the patient. It was evident in the data that family members particularly saw a role for IV therapy in the care of their dying relative. The majority of family members viewed the presence of an intravenous infusion positively, and saw it as a means of providing nourishment:

> *They were feeding him with the intravenous. To me it was a form of food. He couldn't feed by mouth, that was for sure, and I knew it was just sugar and water, but it was a form of food he could have at that time. To me, yes, this IV was feeding him. (Bereaved Family Member #5).*

> *...I was kind of hoping that they would give her intravenous because she wasn't eating and I thought she would have gotten more nutrition from the intravenous. (Bereaved Family Member Interview #6).*

Moreover, in the course of talking about IV therapy with patients and families, it became evident that some people made a clear a distinction between the importance of receiving fluid at the end of life versus food. This was discussed in terms of the comfort fluid afforded the patient:

> *Food is nice, but fluid is necessary for comfort. If she got dehydrated and dried out, that would be uncomfortable for her and I would never push food on her, but I would be worried that she might not drink. (Family Member Interview #3).*

This distinction between lack of fluid versus lack of food was also expressed by some patients:

> *Cause I know that dehydration can kill you a lot faster than not eating. Not eating won't kill you. I have enough fat on me to last for at least 3 months. I've got oodles. (Patient Interview #2).*

Like family members who were "fighting back", family members who were "letting nature take its course" also evaluated the burdens and benefits of such interventions as aggressive oral nutrition, tube-feeding, and IV's. However, for families who were "letting nature take its course", the burden of such interventions were deemed to out-weigh any benefit the patient might enjoy. The notion of burden was cast for these families in terms of physiological burden and emotional distress for the patient. For example, this daughter indicated that her family had encouraged their mother who was suffering from an esophageal tumor to try a trial intervention of tube-feeding, despite the fact that the mother didn't really want to. When difficulties and challenges arose with the tube feeding, this daughter began to re-evaluate the wisdom of that course of action because of its negative consequences or burdens for her mother:

> *When the doctors approached Mom, they said, "This is up to you to decide. Do you want to have the tube feed"? She herself would maybe say no, maybe it was her time to go and see dad because dad passed away a few years back.....We all wanted her to try it.....In a way, we kind of thought we should have listened to Mom because she went through a lot with the tube feed. Like the leaking, and not getting enough food, the medication. They gave her morphine through her mouth and she would cough it up, but if it did go down, it would come out the tube so we never knew how much medication she got. (Family Member Interview #2).*

Some family members appealed to the futility of pestering the patient to eat, or engaging in force-feeding behavior:

> *It never bothered me that she wasn't eating a balanced diet. It was more like, what would you like, because she knew she was dying. I knew she was dying, and what difference is this going to make? (Bereaved Family Member Interview #8).*

Other family members were concerned about the physical and mental distress that the patient would experience as a result of the intervention:

> *Don't force them. You are upsetting them more. They aren't enjoying it. Don't force them. Lots of times they end up sick anyway.(Family Member Interview #6).*

Concerns about inflicting physical and emotional distress on the patient were also expressed in interviews with bereaved family members:

> *... I would probably tell you that it's not worth worrying about. There are other issues to be dealing with, like your other's state of mind. That's more important. Let her have some peace rather than fighting with her to eat. It's the peacefulness that's important. Its not going to make any difference in the short term anyway, but something to keep her calm and keep her happy. Or as happy as she can possibly be in the state she's in. That's more important. (Bereaved Family Member Interview #1).*

The issue of respect for patient wishes was also raised as a reason not to engage in such interventions:

> Q: When your wife was not eating were there things that you would say to try and encourage her to eat more?
>
> *A: No. No, like I said, you have to respect each other and if she wasn't able to eat then I didn't question it... She wasn't eating and if she wanted it, she would have asked me. You have to respect their wishes... (Bereaved Family Member Interview #6).*

Prolongation of a life that had questionable quality to it was also identified by family members as a reason to cease and desist. Said this daughter when asked about the prospect of such things as initiating tube feeding to support her mother's failing nutritional intake:

> *It's not something that we would be prepared to do, and I don't think my Mom would either and certainly when you get to this point I think you are just prolonging things unnecessarily and maybe putting them through stuff that maybe you shouldn't be. (Family Interview #7).*

Another family member remarked:

> *I don't think that she feels that she is having any quality of life now. I don't think she would want anything to prolong it. (Family Interview #8).*

4) Information

Information also affected the strategies used by families in their efforts related to "doing what's best". Two types of information were identified by families as influencing their thinking around the best course of action to take. These included: i) information received from health care providers on the palliative care unit; and ii) information received from other sources (non-palliative care staff, family, friends, acquaintances, and the media).

i) Information Received from Staff on the Palliative Care Unit:

An important type of information received by families was that of teaching provided by palliative care staff. Educational exchanges between families and health care providers typically covered the topics of: a) causes of the patient's weight loss and lack of appetite; and b) the burdens and benefits of such interventions as aggressive oral feeding, TPN, and IV therapy. These exchanges often occurred in the context of health care providers attempting to engage in the collaborative setting goals of care with the patient and family.

a) <u>Teaching about the Causes of Patient Weight Loss and Lack of Appetite</u>

Data from family members indicated that palliative care staff frequently explained and assured them that a decline in intake was an expected event that occurred in terminal illness as a natural part of the disease and the body's "shutting down". Through interaction with health care providers, families reported that dwindling intake and intake cessation came to "normalized":

> *My sister had a chat with the nurse and she said that's just the natural progression of the disease and she said that sort of what happens, you just lose an interest in food. And she's sleeping a lot now and she's just not interested in any and of course here, people aren't keen on eating.....(Family Member Interview #7).*
>
> *The doctor said that when Mom doesn't want to eat. That's part of the disease. (Family Member Interview # 2).*

Health care provider data corroborated family member claims that discussions about what was normal in the dying person regarding nutritional intake did occur:

> *You teach them, that no, I think that what's happening is normal. Three weeks ago he didn't want to eat or drink –that's kind of a natural thing that happens to people. They lose the desire for it. They don't feel like we do, like if we ran a race, or haven't eaten for a full day and are hungry.(Health Care Provider Interview #2).*

However, as palliative care clinicians noted, and as was evidenced in family members who were waffling, the provision of information to families did not always result in an immediate or sustained change in behavior:

> *But no matter how much you taught them that he didn't need all this food, they kept bringing it in stashes of different cookies and baking and noodles and sausage in the fridge..It was just so frustrating because no matter how much you taught them, how much you reinforce, it still continued. (Health Care Provider Interview #5).*

Nonetheless, staff stressed the importance of being patient in repeating and reinforcing earlier teaching that had been done with family members:

> *Some of these people accept it on the spur of the moment, but the next meal they are still force feeding. Yeah, so you just have to keep reinforcing. (Health Care Provider Interview #5).*

In discussing causes of declining intake, health care providers indicated that it was also important to get families to identify that what was happening to their relative was neither an overnight occurrence, nor attributable to staff negligence. Rather, it was important that families come to understand that the deterioration was more likely than not a process that had been going on for some time. One approach used to accomplish this was described by a nurse as "getting them back to their memories". In this approach, the nurse encouraged family members to recount the illness course with the aim of getting them to see that deterioration in the patient's status generally, and nutritional intake specifically had occurred in the form of a steady, progressive decline:

> *I think it's meeting them on their own grounds and saying, or you teach them, that no, I think that what's happening is normal. When you brought him in 2 or 3 weeks ago, how was their appetite. Has it changed? Did you feel that they had lost weight before you brought them in. Is there a change? We get them back to their memories so they can see that it has been going on for a long time... (Health Care Provider Interview #2).*

Though health care providers reported that they often explained to family members that the cause of the patient's marked weight loss and lack of appetite were due in large measure to the patients advanced malignancy, they also stressed that it was equally important to dispel the notion that every instance of anorexia and dehydration were indicative of imminent death. Health care providers noted that in some instances, patient difficulties eating and drinking was more apt to be due to the exacerbation of a previously controlled symptom(s) or the appearance of new ones. These causes of difficulty were quite possibly amenable to intervention, and with such intervention would come a restoration of intake:

> *It is complicated. When you are looking at real physical reasons and someone's come in with nausea, vomiting, emesis, then they are quite right in the idea to get their hydration back up because of the chance of them going back home and eating again. So you have to find out why are they not eating. If someone is nauseated and vomiting and that's the reason they are not eating or drinking...if you correct that problem, then maybe their appetite will come back. We can try and correct nausea and vomiting and see if their appetite comes back and they start to eat or drink, but if its because they are deteriorating.....(Health Care Provider Interview #4).*

b) Teaching about Burdens and Benefits of Interventions

When family members wanted to "fight back" in situations where staff felt aggressive intervention was not appropriate, information was provided to families about the potential burdens of such interventions. Through these interactions, palliative care staff hoped to educate families both about the limited efficacy of food and fluids in improving the patient's condition, and the potential "down side" of such interventions. The "down side" was most often characterized in physiological terms:

> *I try to educate...I try to tell them the pluses or minuses of the hydration. Especially when we're talking about patients who may be days or even hours within death. Uh, I talk to them about the fact that uses, the hydration is important for the management of certain symptoms. If the person is symptomatic with the dehydration or if he has a toxicity from opioids and he's delirious because of dehydration, well then I think we should treat that. (Health Care Provider Interview #3).*

In addition to outlining specific deleterious consequences of certain interventions, health care providers would also cast either not starting or stopping an intervention in more positive terms, such as how this might afford the patient increased comfort:

> *I try to put it in the context of "how can we make your loved one more comfortable?" Well, we've gotten rid of certain medications. You know they still have an IV in . That's excess fluid. It may be causing them more harm than good. You know, that's something we could discontinue. (Health Care Provider Interview #11).*

The educational exchanges between family members and health care providers clearly helped shape the thinking and decision making of some family members, particularly when such information appeared intuitively correct to them. That is, the information they received from health care providers about the burdens and benefits of particular interventions made sense:

> *When she was brought here to palliative care and I was talking to the staff and they said not to be concerned with the amount of food she eats, it was the quantity of the liquids she drinks was far more important than what she was eating. And they said no matter what she ate, the way I felt that they meant, that if she ate a full breakfast and a full lunch and dinner in the evening that it wouldn't improve the spread of the cancer. It's not going to improve her disease or it won't give her anymore time sort of thing. It's not going to be a cure so they told me not to be concerned about it.*
>
> Q: And how did that explanation sit with you?
>
> *Well, it made sense. I could understand that. If you are dying and you have cancer it's sort of something that's eating away at the body so if you feed it it isn't going to stop it...So going on that basis, I haven't been trying to pressure her to eat or anything....(Family Member Interview #8).*

In contrast, family members were not apt to reflect upon or alter their preferred course of action related to nutritional care when they found information they received from health care providers to be blatantly counterintuitive:

> *The doctor talked to us about the fact that it didn't do any good to force food, because it doesn't make a difference anyway. Well if you don't have gas in the car, you're aren't going to go anywhere.(Family Member Interview #4).*

> *... and [my sister] said they told me I shouldn't eat that much anymore and I said, who told you this?... and she said they told me not to eat because the cancer grows too fast. If you don't eat, the cancer doesn't grow... Somehow I don't believe that... if you eat and the cancer grows, and to stop the cancer from growing, and you don't eat, you die any ways because you need food. (Bereaved Family Member Interview #9).*

The issue of trust in the health care provider appeared to influence to what extent family members believed and accepted information received:

> *When they brought him upstairs they did have an IV in, and we discussed it. I had a long talk with the doctors and that was it. They said, it was best to take him off it. I said, fine, you know, I trusted them. (Family Member Interview #5).*

> *... and when the nurse said, "we are going to order only a few liquid stuff", I knew she knew what she was doing because they see so much of those things... because the staff over there are very good and they know what they are doing because they see that all the time and I don't think it was my decision the way he should eat or not eat because they know more than me at that point. (Bereaved Family Member Interview #2).*

Health care providers also identified the importance of being competent as a way of instilling trust in family members:

> *Are you watching, are you caring? I think it's the whole thing of trust with them and I don't mean you have to talk it. You have to show it in someway because they are going to watch. That's the big one, because it comes down to do you really care about this person. Only a good show of competence helps those issues out... ... if you have been taught as staff, and you as a caregiver really know what you are talking about and you know its true, then its not really an issue.(Health Care Provider Interview #2).*

In the course of educating family members about the burdens and benefits of a given intervention, health care providers indicated that they spent considerable time correcting misperceptions about what an intravenous (IV) could and could not do, with respect to providing nutrition. Given the fact that many of the families when asking for an intervention asked about the initiation of IV therapy, this finding is not surprising:

> *"...a regular question is about IV"s. A lot of people are misinformed, they feel an IV is providing nourishment. So that is something you always have to reinforce. (Health Care Provider Interview #5).*

> *They say, "you don't eat anything, but at least you've got that going, and we, then we give some explanations that it doesn't really have any calories in it. (Health Care Provider Interview #10).*

While health care providers were clear that IV therapy did not amount to nutritional support for palliative care patients, they were less clear about the other possible benefits of IV therapy in terms of overall comfort care. They noted that discussions with family members regarding the issue of hydration in this way was complicated by the fact that the empirical literature regarding the benefits and burdens of such an intervention are inconclusive.

In addition to teaching families about the potential burdens of IV therapy, and correcting misperceptions about what IV therapy could and could not do, health care providers also identified they felt that IV equipment may become a technological barrier between patient and family, and hence be a psychological burden:

> *Uhm, that's just another form of technology that may be getting in the way of the family. You can't touch that hand that's got the IV in it. You know, don't do that dear, it's going to set off the machine. So, if you take out the IV, suddenly the family can get closer. They don't worry about that little bit of technology or whatever there. And.. And in some cases, that's a very important thing. (Health Care Provider Interview #11).*

Several factors were identified in this study that appeared to influence the nature of the teaching that occurred between health care providers and family members. First, the ethos of a palliative care unit appeared to influence the perspective of health care providers about hydration in terminal illness, and hence the ways in which they educated patients and families about this issue. Unlike some palliative care units that have a standard policy with respect to hydration, the staff working on the unit in this study stressed the importance of taking each case individually where decisions regarding hydration were concerned:

> *Now in City X, people in City X will argue–well if you don't put that in, maybe they die in delirium. All the results have shown us that 90% of our people die in delirium whether they're hydrated or not. I know that there are essentially two camps on..on hydration when we talk about doctors and nurses and where I trained, that's solidly one camp. But here, I think we've kind of said, okay. Let's use hydration ...uhm, judiciously. Appropriately. You know take every patient for its own sake. (Health Care Provider Interview #11).*

A second factor affecting the nature of educational exchanges between health care providers and family members concerned the health care provider's assessment of the ability of families to be able to grasp the information intellectually. This assessment influenced the level of complexity of information provided to families:

> *It depends a lot on the sophistication of the families about how much I talk about studies and TPN, and so it may be a little more basic. (Health Care Provider Interview #10).*

Third, the ability of the family to handle information related to the burdens and benefits of interventions on an emotional level also influenced the exchange of information between family and health care provider. For example, Health Care Providers in this study were clear about the types of situations they believed would warrant IV hydration and those in which such intervention was either unwarranted, or would constitute an unnecessary burden to palliative cancer patients. Interventions that were clearly not warranted were referred to by health care providers in this study as the "no-option" option:

> *When there really is not an option in the first place, we shouldn't be offering it to the patient. Uh, the patient may be able to take things orally. He's doing very well. Even though you're deteriorating, you're not complaining of thirst, you don't look dehydrated, you're not symptomatic... We shouldn't be offering it, because if we do offer it, the family looks at it as maybe being the be all and the end all. This is the saving grace. This is going to keep dad or mom alive for x number of weeks (Health Care Provider Interview #10).*

However, if the health care provider perceived that the family was just not emotionally able to handle the removal of an IV that was already in place, they would leave it in place and either delay, or in the case of the imminently dying patient, not broach its discontinuance with family members. Such situations were characterized by: i) the presence of an IV in an imminently dying patient who had been transferred from the emergency department, intensive care unit, or other ward; and ii) the health care provider's perception that families were not able to "let go" of their dying relative in the context of a rapid downhill illness trajectory. Health care providers felt that it was important not to add to family stress by removing the IV, as long as the infusion did not exacerbate symptom distress. It appeared that such decisions served to minimize distress and regret in family members–both in the clinical moment and in the bereavement period:

> *I think that families, especially if they are transferring, more so if they are transferring from ICU. The families have been dealing with a number of transitions all at once. The perception that food and fluids are vital and critical, and giving them is vital. And that perception is so pervasive that if you can just pull it out, then it would be too much of a contrast...(Health Care Provider Interview #10).*
>
> *We have transferred patients from other wards that have IV's continuously all the time. Some of the families really insist that we don't stop it. Then it would be left there, but you wouldn't leave it in a patient that was edematous from head to toe and are filling up with fluid. But then that's explained to them. If its not going to hurt the patient, and the family is really grieving, then it does help them to leave*

> *it in. You don't want families to be saying after they [the patient] have died and they pulled everything off and they did nothing for them. You don't want them to be saying that. Its traumatic for families (Health Care Provider Interview #3).*

Health care providers would thus "quasi-continue" the intervention. For example, if an IV was in situ and not harming the patient, they would leave it there and turn the infusion rate down to run very slowly, to keep the vein open (TKO):

> *If they come up from emergency and we thought they were dying...we drop the IV to TKO, to 30 mls an hour. We know it's doing nothing, but you really have to give the family some time....(Health Care Provider Interview #2).*

While a rapid downhill trajectory tended to influence whether or not the IV was removed, health care providers indicated that sometimes even in the face of steady slow deterioration during which the patient had been on the palliative care unit and staff had repeatedly talked with the family about IV therapy, that some family members would find discontinuing that intervention close to death unbearable. Thus, the same sensitivity was also extended to family members whose relative had been on the palliative care unit all along:

> *And sometimes we will say, you know, continue it [IV] but we'll put it low so you're not causing problems. Uhm, some families just aren't in that space even though....even though this lady is going to die within an hour or a day. We won't discontinue the IV because no matter how much you've educated, you just can't get them to that stage. So you say, fine. But then you turn it down to TKO knowing that the least amount of damage is going to happen and you try to make things as best as possible....If they can go there, we'll take it out. If they can't, we'll leave it in ...because its important for them, but we'll try and minimize its impact while its in place. (Health Care Provider Interview #11).*

Clearly, the psychological impact of care decisions on family members, both in the clinical moment, and later in the bereavement period also influenced health care provider behavior regarding the initiation or discontinuance of certain interventions.

Interestingly, there appeared to be a parallel process operating between family members and health care providers. That is, just as family members engaged in specific behaviors with the aim of doing what's best in order to decrease decisional regret, so too health care providers engaged in clinical decision making that was likewise designed to minimize family member regret. This sentiment is well described in the health care provider data exemplars below:

> *Nobody wants to leave them with any regrets and we don't want to leave them with any decision that they have to live with for the rest of their life... its that last dealing with the person that you carry forever and I'm sure your view is colored by the meaning of the actions, as to the meaning behind why there's an IV or why there's no IV, or why there's a tube feeding or no tube feeding. That sort of thing... We are not imposing things on them, but giving them some voice...(Health Care Provider Interview #7).*
>
> *Some families have a great deal of difficulty...so that... you're not forced into doing the IV, but you know if you don't that they're going to remember that for the rest of their lives. "Oh, he died and he didn't even have an IV. And that's not fair...(Health Care Provider Interview #11).*

In addition to teaching family members about causes of weight loss and anorexia and the burdens and benefits of certain interventions, health care providers, notably nurses, provided information and role modeling with respect to ways that the family could participate in the physical care of the patient:

> *What you can do is show how they can participate in their care and they are shown how to do mouth care safely. We show them how to do mouth swabs, moisture swabs... Then they feel involved with the care... (Health Care Provider Interview #2).*

The role of nursing in this regard was also identified by other members of the health care team:

> *It's often a nursing issue to teach families what's appropriate care and they can do something else, because often it's a way of managing their helplessness in the situation. So if I feed I look after this part and it is something I can do for this person or for my loved one. So they are trying to push it and staff members try to help them find another way that they can be of use and not feel helpless and face the fact that their loved one is dying. (Health Care Provider Interview #7).*

In the course of modeling behavior for family members, nurses also availed themselves of the opportunity to reinforce earlier teaching:

> *What we often do is just moisten their mouth and just keeping the mucous membranes of the mouth moist often prevents thirst and so they are comfortable and our emphasis is on comfort and in doing that..we are not anticipating thirst and hunger to be there and in our experience it isn't. (Health Care Provider Interview #4).*

The information family members received from health care providers appeared to serve a two-fold purpose. First, educational exchanges were designed to educate and hopefully promote a change in family behavior, particularly when that behavior was of the "fighting back" variety. However, these interactions were also seen by health care providers as a way of helping family members begin to deal with some of the anticipatory grief they were experiencing:

> *I can go along with families' requests to hydrate, but the same thing applies. This is sort of a method of denial, or something to hang on to and often when you present the data and show how little clear benefit it is...I am more or less helping them along to the next step. I am using this as a method to open a door to help them along with their grieving and acceptance. The truth needs to be brought out and dealt with. (Health Care Provider Interview #4).*

While information did have the potential to help family members be able to come to terms with the inevitability of the patient's death, and thus cause a shift in their orientation related to doing what's best, health care providers were aware that some family members would not or could not re-evaluate their stance in this regard. That is, they remained "stuck" and continued to engage in fighting back behaviors:

> *And trying to move her along with her acceptance of his dying and I came to a point where I realized that she was never going to get there... she would have to deal with it and some people are like that and again, you can't beat down that denial with a stick. It's not helpful to those people. (Health Care Provider Interview #7).*

ii) Information Received from Other Sources

In addition to receiving information from palliative care staff, patients and families some times received information--erroneous information-- about what "should be done" with respect to nutritional care from health care providers who did not work in the area of palliative care. Typically, these health care providers had been involved in the patients' care previously (for example a surgeon, or family physician,) or were members of the dying patient's family. The provision of mis-information by these individuals about what constitutes appropriate nutritional care in terminal illness frustrated and angered the palliative care staff in this study:

> *...that really burns my butt. You've worked with the family. You've brought them to a certain level of understanding where all are understanding and this idiot who doesn't know anything about where we're at, comes in and offers to do this. Uhm, probably well meaning. And, from his or her viewpoint, its' like, "Oh my God, my patient is going to die. We have to do something. Uhm, but it opens up a whole can of worms and we've got problems again...Like you know, we've gotten to a certain point here...Please don't meddle. I don't come into the OR and tell you you're using the wrong scalpel or I would use this stitch instead. Ah, you don't come in and tell us what we're doing here. ...And we are working as a team. Don't come in and muck it all up. (Health Care Provider Interview #11).*

Another health care provider suggested that just as the lay public are frequently misinformed about the nature of palliative care, so too are clinicians who have no palliative care experience:

> *It's simply not hand holding, and wiping the tears away and empathy and that's a very important part of it, but there is such a good science to it. I think it is a great mix between science and art...Often people are quite surprised when they consult you and you give them all this knowledge and basis for where you can get the patient a lot more comfortable with all their symptoms. Certainly, education of not just the public but the medial mainstream should be out there. (Health Care Provider Interview #4).*

Another source of information for families arose from the interactions with other families who also had a terminally ill relative receiving care on the palliative care ward. Field work supports the fact that family members do interact with one another in the clinical setting, discuss and compare care regimens, and make observations about the types of care different patients on the unit receive. However, the information that family members receive in this way, particularly in relation to what constitutes appropriate nutritional care, may be neither appropriate nor applicable to their relative. That is, each patient situation, and the response to that situation by the palliative care team is individually tailored. This issue is further complicated by the fact that some acute medical patients who are not "palliative" are also housed on the palliative care unit. Thus for some family members, the care being received by their terminally ill relative may appear wanting or lacking compared to some of the more "curative" interventions being received by others.

Palliative care staff identified that family members do in fact glean information in this way and often make unfavorable comparisons. Staff felt that such situations were best dealt with pro-actively:

> *Then you get families, because they are watching each other's families and they really do. It's a huge issue. They will watch all these bags going into someone else's room and their husband could be dying and he's getting nothing. They see an awful lot of people coming there and giving all these bags and stuff... My*

> *husband is lying here and getting nothing. The families talk to each other... A lot of misinformation gets passed on. [I say] you're right, You do see a lot of stuff going in there and you might be wondering why he's getting stuff and not your husband. (Health Care Provider Interview #2).*

It was also evident in reviewing the data that families received information from a variety of "non-health care professional" sources. Typically these were friends and acquaintances of the family. For example, this family member indicated that her husband had received information about complimentary therapies from his barber, who told him that the tablets he recommended were designed to help the body to "fight cancer" and prevent further tumor development:

> *... they had a little conversation about cancer and she spoke about her brother having it and he is on various vitamins from the Bay so I spoke with this women and $300 later with these various things. And he would take about 10 of these tablets. There would be these enzymes, shark cartilage,...there was calcium, garlic... (Bereaved Family Member Interview #10).*
>
> Said another family member:
>
> *We have a friend, C., who is into reflexology and she used vitamin and minerals so we said why don't you ask C and so she did. I guess she thought it might control it [the cancer]. Just to sort of build up her own resources so she could keep up the fight. (Bereaved Family Member Interview #8).*

A bereaved family member explained that her husband had received nutritional counseling and direction to take certain supplements in order to prolong his survival. While she knew that it wasn't a "regular doctor" who had initiated this plan of care, she was not exactly sure just what the person's qualifications were:

> *The first couple of months they gave him herbs and he went on a very strict diet. No dairy products, no butter or meat. They put him on mostly salads, green stuff, and the herb.*
>
> Q: Who put him on that?

> *Umm...that place on Pembina Highway. They have an office there. They have herbs there. They're supposed to be specialized. ...Those herbs won't cure his cancer, but its going to keep him going longer. Cleaning out the system, and I really believe in that because they took a scan in December and another scan in February and there hasn't been any change (Bereaved Family Member Interview #2).*

Finally, health care providers implicated the influence of the media as an information source contributing to the expectations of family members regarding particular interventions related to nutritional care. The influence of dramatic television programming dealing with hospitals and health care (e.g. Chicago Hope and ER) was implicated by health care providers as being particularly influential in shaping family member expectations:

> *They see it on TV. They always get an IV. They do that for the story (Health Care Provider Interview #2).*

5) Experience

The information that family members had gleaned as a result of past experience, either through caring for another relative with cancer or other illness or their own hospitalization also appeared to influence the extent to which family members would fight back as opposed to let nature take its course. The data suggests that past experiences with previous hospitalizations, particularly where IV therapy was used, influenced expectations around the use of IV therapy in the palliative care setting. For example this family member credited the IV therapy she received during an acute illness with saving her life, and thus thought it could play a role in the care of her dying husband:

> *I was in the Intensive Care Unit and I was connected to all those things. An IV, the one that was given to me was to save my life. It was keeping me alive...(Bereaved Family Member Interview #5).*

In contrast, past experience with pulmonary edema made this family member wary of her dying relative receiving too much IV fluid:

> *That one [the patient getting an IV], I was worried about, that one. "Cause if they give you too much fluid, then you can go into heart failure. I asked the doctor and he said we'll watch it real close and for a day they watched him...They were watching him. (Family Member Interview #1).*

Health care providers indicated that issues around IV therapy were often raised in terminal cancer care because the use of such an intervention is standard practice in acute care areas. That is, IV's on such units are routinely "left in till the end". Thus, the presence of an IV in a dying patient may constitute standard practice in the minds of some family members. This expectation then gets generalized to the palliative care setting:

> *In my experience, it's not an issue on other wards because the physicians who are looking after them [the dying] maintain their IV's till the end...it's a problem with the physicians stopping the treatments, which they don't. So the issue doesn't happen with family members there, because the IV's are running till they die. (Health Care Provider Interview #3).*

Health care providers also speculated that families' past experience with the more "curative" part of their relative's cancer trajectory also sensitized them to the importance of avoiding dehydration:

> *It [dehydration] is a word they've heard and probably have heard throughout the course of the illness with chemotherapy and when you start running into problems and we don't want them to get dehydrated. So we give an IV. And things like that. They've been all through that. (Health Care Provider Interview #3).*

Past experience did not always mean that families always petitioned for interventions, however. For example, while some family members reported that their dying relative had tried complimentary therapies in the past, other family members reported that experience with deleterious side-effects had made some of them change their minds about using certain products:

> *We have a relative who came over one day with some tea and said, "try this, it's supposed to be very good. It's supposed to combat the cancer. And this was about 5 years ago... so she stared drinking this tea and my father kept reading the ingredients and kept telling her, "don't have too much. There's no warning on here but your kidneys are gonna shut down." And she recommended this stuff to a friend of hers who also had the same cancer and she died about three weeks later from kidney failure. And she threw the stuff out. That was it. She never touched anything else after that. (Bereaved Family Member Interview #1).*

Additionally, for family members who were letting nature take its course, the experience of having cared for another relative or friend with advanced cancer had taught them that aggressive nutritional intervention did not alter the outcome:

> *You have to let nature [take its course] ...that's the way with cancer and I know because I lost two people in my family and that's what happened. (Bereaved Family Member Interview #2).*
>
> *I feel it [his intake] is very poor and I have seen a lot of people pass away and towards the end they just can't eat ...... (Family Member Interview #9).*

Sometimes, more immediate experiences in caring for the patient taught family members about which interventions would work and which wouldn't. For example, this wife recounted what she had learned about the efficacy (or lack thereof) of trying to give her husband fluids using a procedure she had devised using a sponge:

Q: Did you worry that he was thirsty?

> *A: Oh yes. When I would go and see him I would take a sponge and soak it in room temperature water and let it drop in his mouth... I was afraid that he would choke. One day he did cough quite a lot... then I never tried that again. (Bereaved Family Member Interview #5).*

Past experience also taught family members about what they could do for the patient in lieu of feeding. This widow indicated that her experience in caring for her dying sister had taught her that there were other things she could do that were comforting that had nothing to do with food. The behaviors described below are very reminiscent of the behaviors previously detailed that are associated with "being there". To that end, past experience appeared to inform family members about what they might do in the course of "finding other ways to care."

> *...and I remember my sister telling me, "If only you come in and hold my hand, instead of my trying to talk." She said, "I would feel better." So I would hold his hand and if he wanted to talk he would talk, but not force him. (Bereaved Family Member Interview #5).*

Health care providers concurred that family members' past experiences had the potential to shape their responses and expectations to the type of care their relative would receive. Past experience thus influenced and shaped the care audit criteria against which family members evaluated the care provided to the patient:

> *They'll say, "well, when Aunt Marge had an IV she just really came along." That's why you really need to know what people's issues are and what they are basing their thoughts and beliefs on. (Health Care Provider Interview #9).*

One type of experience that family members bring to the palliative care arena that may influence their care expectations around food and fluid is that of their cultural experience. Family members and health care providers concurred that culture and the behaviors related to food are closely linked. Some cultural groups were characterized as being very concerned about food, and the feeding of the patient:

> *Yes, this business of feeding someone. Well, I know in the Ukraine culture, food is very important and I can see how our people would be very anxious and say, "eat some more." (Bereaved Family Member Interview #10).*

> *I think about this one man's family, they were from a good German family. She was a good cook. that was important to them, a good big meal and to eat was important to them, that was a big thing with her. Food was a big thing for this family. In this case, the culture was food. (Health Care Provider Interview #2).*

> *This one woman had some difficulty with her husband when he didn't eat and he went downhill. She had a hard time. I guess the Italian's are that kind of breed where you eat and eat and eat. Well he didn't. (Health Care Provider Interview #6).*

In contrast, food was perceived to figure less prominently in other cultural groups:

> *Like the Mennonites, they use food a different way. They don't push it on the dying person. They seem really good about that...But the Mennonites feed the staff. We get lots of food from them. They bring homemade bread and cheese, and they feed us well and they feed each other but they don't bring it to the dying person. (Health Care Provider Interview #2).*

6) Readiness to Let Go

Family member readiness to let go of the dying patient emerged in the data as being an important factor that influenced the extent to which family members could let nature take its course, as opposed to pseudo surrender, or fight back. Readiness to let go refers to the willingness of the family member to begin to detach and disconnect emotionally from the dying person. Families who were entrenched in fighting back or pseudo-surrender behaviors were seen as having particular difficulty in this regard:

> *It comes up as an issue for families... for the person in terms of their not being ready to let go and sometimes they aren't able to have a dialogue. (Health Care Provider Interview #8).*

> *The family member may be taking it as a personal thing, if you loved me you would eat that, cause you would want to stay with me longer and I'm not ready to let you go and I have heard one lady saying that "I'm not ready to let him go I know he's ready, but I'm not ready and as the time came closer she wasn't ever totally ready but she got to see more of the inevitability.....(Health Care Provider Interview #7).*

Family members who were having difficulty letting go were also characterized by health care providers as feeling particularly helpless and frightened:

> *Their helplessness escalates and they...might be more forceful or more aggressive in terms of, "Oh, you have to eat. You have to." And often what they're reflecting is their own difficulty in dealing with letting this person go." (Health Care Provider Interview #9).*

A bereaved family member who had adopted a "letting nature take its course" approach also speculated that feelings of helplessness may affect the behavior of family members who engaged in more aggressive feeding behaviors :

> *The one doing the forcing, be it the wife forcing the husband to eat, all be it not intentionally selfishness, but she might keep it in the back of her mind, if this person dies, what am I going to do? (Bereaved Family Member Interview #8).*

Family members in this study who were fighting back validated that they experienced such feelings at the thought of the loss of their loved one:

> *There are so many things that terrify you. That's the word. You are terrified. Actually, what you try and do is take each day and see what happens, because you cannot think too far in the future. There will come a time when he can't eat. So you just have to push it away. (Family Member Interview #10).*

In addition to feelings of helplessness, health care providers also speculated that family members who experienced strained relationships with one another also had difficulty in letting go. Typically these were families who were described as having longstanding histories of unresolved conflict, and/or whose members were estranged from one another:

> Q: Can you, in your experience anticipate about which families could be more or less problematic around the area of nutrition and hydration?
>
> A: *So called dysfunctional families who are kind of reactive. You know, they hate the guy's guts and you're glad he's going to die cause he's a jerk, but you can';t live with those feelings , so therefore you do everything possible for him. No matter that he's not a decent husband or he's an alcoholic dad (Health Care Provider Interview #10).*
>
> *If there's been a lot of strife and conflict in unresolved issues in the history of that family. Then it's a tornado just waiting. So I mean, that's very typical (Health Care Provider Interview #9).*

Health care providers also indicated that family members who lived out of town from their dying relative sometimes tended to have more difficulty with care decisions that reflected a "letting nature take its course" perspective. In such cases the desire to feed was seen as being a way assuaging the guilt the "out of towner" felt about their absence, and limited contributions to the patient's care:

> *The "out of town" person is another scenario. It's a feeling of guilt when you do everything you possibly can. Often it's a family that's not very close, and it's a way of compensation for the lack of closeness (Health Care Provider Interview #10).*

7) The Symbolic Meaning of Food

The meaning family members ascribe to food and fluid constituted an important intervening factor in this study. It was evident from the data that the provision of food and water carried a variety of symbolic meanings for these individuals. First, families identified food and water in particular, as being critical to patients' survival. Therefore, the idea of not instituting measures to provide the patient with life giving sustenance, or discontinuing such measures if they were in place was inconceivable–even if such interventions were potentially harmful to the patient:

> *In many patients, an IV shouldn't be an option. Uh, you know, the patient has far too much fluid already. There's fluid overload, their lungs may have excess fluid. Ah, for us its kind of a no-brainer. But ah...the family still see it as you can't let go. This is my "life-line", sort of. (Health Care Provider Interview #11).*

These symbolic meanings explain, in part, family member behavior related to the targeting of patients of take in increasing amounts of food and fluid, and of health care providers to institute measures to support nutrition and hydration. It also explains why information about the burdens and benefits of a particular intervention is insufficient to potentiate a change in family member thinking around nutritional care issues.

Second, food and fluid have a communal aspect to them in that they are frequently shared and enjoyed with others. To that end, there are social meanings ascribed to the provision of food and fluid. All patients and family members indicated that the ways in which they had once enjoyed eating and interacting at meal times had markedly changed due to the patient's illness:

> *Oh yes, I would have to eat in the other room and make sure his door was closed because he couldn't stand the smell. I'd have to grab something quick.... (Family Member Interview #5).*

The importance of the social aspects of eating, and the ways in which they were affected by terminal illness was also identified by health care providers. One respondent described the loss of social interaction that occurs because of problems with anorexia and other symptoms as "unlinking':

> *I mean eating is a social phenomena and when we stop eating, that takes you out of that...that social group. And suddenly they don't belong, or they don't come to that. They..they can't partake in that. That's another, unlinking if you will. You know, the person is linked to the family or the caregiver and suddenly, there are certain things that unlink them. Push them further back. And that's one of the big things, the unlinking (Health Care Provider Interview #11).*

Finally, the provision of food and fluid is associated with care and nurturing:

> *I think you can call it love in a sense. Its about obligation and responsibility. Family often show a lot of love for their family member who is dying and one of the most basic tenets of care in everyone's society, no matter what culture you are from its feeding. The basic staple of human concern. You look at parents feeding and nurturing their kids all the way to the kids feeding their parents and looking after them as they get old. We can't let someone starve to death is the bottom line. (Health Care Provider Interview #4).*

> *When we deal with a person we want to give them something and in our culture we feed people. That is the way we show people that we respect them and we are being sociable and we care..to the family member even more so. (Health Care Provider Interview #2).*

Summary

This chapter identified the seven intervening conditions identified in this study that influenced the strategies and behaviors families embraced in the course of doing what's best. The ways in which these conditions served to either facilitate or constrain family behavior was described. The next chapter will examine the study's findings in light of existing literature. Limitations of the project will be discussed, and recommendations for practice and education will be identified. Directions for future research will also be provided.

CHAPTER TEN:

DISCUSSION AND RECOMMENDATIONS

Introduction

The purpose of this study was to contribute to an understanding of the ways in which family members of terminally ill cancer patients balance the means and goals of nutritional care while meeting their own needs in relation to the provision of such care. The model that emerged from the study, that of "doing what's best", will now be discussed in light of the work of other researchers and relevant literature in the field. Limitations of the study will be discussed. The chapter concludes with a series of recommendations related to how the emergent model has implications for nursing practice and education. Suggestions for future research are also provided.

The Model and Military Metaphor

A striking feature of the model is the extent to which many of the key conceptual categories and associated strategies are imbued with military metaphor. Gordon (cited in Hobus, 1992) notes that the most important requirement for an effective metaphor is that it meet the individual at his model of the world. That is, the metaphor preserves the structure of the individual's problematic situation. Linkages between military language and cancer have appeared previously in the literature. For example, in her book Illness as Metaphor, Susan Sontag (1979) uses military language in describing the cultural meanings of cancer. In this excerpt from her work, cancer is characterized as the "enemy invader":

> Cancer cells do not simply multiply: they are invasive. Cancer cells colonize the original tumor to far sites in the body, first setting up tiny outposts.... Treatment also has a military flavor. Radiotherapy uses the metaphors of aerial warfare; patients are bombarded with toxic rays. And chemotherapy is chemical warfare (Sontag, 1979, pp. 62-64).

Family members in this study appeared to understand and respond to the problematic situation of declining intake in their terminally ill relative in terms of a battle-complete with tactics and strategies related to both attack and counter attack, to war and peace. Such a conceptualization is consistent with Wurzbach's (1999) examination of the ways that metaphor become operationalized in everyday life. That is, the metaphor of war and its related concepts appeared to structure and reflect what families perceived, and how they acted and related to other people regarding nutritional care in the face of terminal cancer.

The literature that describes societal attitudes toward cancer, and death and dying is helpful in understanding the model that emerged from this study, and the military metaphors that permeate it. First, despite increased public awareness of death-related issues, we remain largely a death denying culture (Kastenbaum, 1998; Kalish, 1985; Rando, 1984). Advances in biomedical technology during the latter part of the 20th century have, as noted by Steinhauser and colleagues (2000), "propelled us to see a "good" death as one involving the fight against disease. Indeed, burgeoning technology makes it possible for such just such a struggle to occur and sets the stage for dying individuals to experience what Callahan (1994) has described as a "full-court" maximum technological effort to keep somebody alive (p.180).

The appropriateness of fighting back, even in the face of advanced disease may also be communicated to the public in more insidious ways. For example, Kristjanson (1997) has observed that The Canadian Cancer Society slogan "Cancer Can Be Beaten" may well communicate a belief that individuals should fight to get well and that the "correct" way to die is to continue to struggle toward a cure" (p. 56). Fighting back behaviors would thus appear to be socially sanctioned.

Second, Vachon (1977) noted that cancer in particular is a disease is associated with "evil, dirt, pain and death" (p. 269). Parker (1981, cited in Benner and Wrubel) added that cancer engenders deep fear in society about, "the inevitable decay and disintegration of the body. The societal "battle" against cancer is thus seen as the struggle to resist acceptance of the inevitability in life of death, decay, and decomposition." (p. 8). Cast in these terms, the decision "not to fight" would appear to be almost an indefensible one!

Third, because denial is a common response to death and dying in north American society (Kastenbaum, 1998), it is not unusual to hear that term invoked when patients and family members behave in ways that seem to disavow knowledge of a terminal disease. Not surprisingly, family members engaged the sub-processes of "fighting back" or "pseudo-surrender" were sometimes characterized by health care providers in this study as being in "denial". However, use of the term denial in this way warrants closer examination. From a psychiatric standpoint, denial is seen as a primitive defense mechanism in which an individual denies the existence of threat (Kastenbaum, 1998). However, interviews with family members using "fighting back" or pseudo-surrendering strategies, suggests that these individuals were not denying in the psychiatric sense of the term. Rather, it appeared that they were coping with a difficult situation in the most resourceful way they saw possible. Moreover, family members who were fighting back and pseudo-surrendering were frequently fearful, angry and sad. These responses to the cancer illness are normal ones. Indeed, it might be argued that it is not the presence but the absence of such feelings that is apt to suggest that denial is operating.

If denial does not adequately capture what is happening with family members who are fighting back or pseudo-surrendering, how might we explain what appears to be a lack of family member understanding or insight into the terminal quality of the patient's illness? Weisman's (1972) writings about the concept of middle knowledge may be instructive in this regard. Middle knowledge reflects a state of both knowing and not knowing about the fact that death is near (Weisman, 1972). More specifically, in middle knowledge, "awareness and denying often run together, crossing over as one emotion or perception gains ascendance and blurs another (Weisman, 1979, p. 45). This description appears to provide a particularly cogent explanation for the waffling behaviors seen in family members who are pseudo-surrendering. Thus, while middle knowledge has primarily been described with specific reference to patients, it would seem, based on the findings of this study, that family members experience something similar.

The "letting nature take its course" sub-process of the model stands as the antithesis to the behaviors associated with the sub-process of "fighting back." The juxtaposition of these two sub-processes bears a close resemblance to the differences and tensions between medical interventions that are oriented toward cure as opposed to comfort care. That is, the objections to "fighting back" articulated by family members who embraced a "letting nature take its course" approach are consonant with those of the hospice and palliative care movement who are concerned as to the appropriateness of aggressive curative efforts being foisted upon the terminally ill. Such shifts in orientation do not come easily, for as Bennahum (1996) observed, the hospice and palliative care movement has had to"... challenge the prevailing view that death is a failure of medicine and something to be hidden" (p.8).

Families who were letting nature take its course in relation to nutritional care had come to question the wisdom of aggressive nutritional intervention, and expressed concern regarding its potential negative impact on the patient's quality of life. Instead, they demonstrated a shift in focus that was more holistic in its orientation, as opposed to focusing solely on the management of symptoms related to decreased intake. The behaviors in which they engaged during the process of letting nature take its course were not analogous to "giving-up." Indeed, the group of behaviors identified in this study associated with the conceptual category "finding other ways to care" challenges prevailing notions that "there is nothing left to do," for individuals in the terminal phase of their disease.

Strategies Identified in the Model: Relationship to the Literature

Fighting Back: It's Best to Eat

Family members in this study who were fighting back engaged in a variety of strategies that had the goal of getting calories into the patient. These included the use of such strategies as monitoring and gauging intake, begging, coaxing, nagging and force-feeding, and manipulating food. Several of the actions or behaviors associated with these strategies are consistent with those reported in the literature.

First, the findings of this study support the findings of a phenomenological study of caregiver perceptions regarding intake cessation in terminally ill cancer patients (Meares, 1997). That study detailed actions taken by caregivers in order to maintain and/or restore intake patterns of terminally ill patients. As was the case in this study, caregiver behaviors included such things as monitoring the patient's intake, tempting the patient with favorite foods, offering a wide variety of choices, and adjusting portion sizes Meares (1997) also identified the presence of force-feeding behavior in her study. It was mentioned by only one of her twelve respondents however, and thus categorized by the author as a contrary case, suggesting that such behavior was rather rare. In contrast, the findings of this study suggest that, while not an everyday occurrence the behavior of family members force-feeding their terminally ill relative was more commonplace.

Second, family members who were fighting back engaged in auditing behavior. This behavior occurred within the context of targeting the health care provider. Auditing behaviors provided a mechanism whereby family members could evaluate the nutritional care the patient received and compare it to their perceived ideal. The extent to which nutritional care fell short resulted in a cascade of further activity designed to redress the shortcomings identified in care provided. Family members in this study identified that when they made special efforts to be in attendance on the palliative care unit, particularly at meal times, to compensate for what they perceived to be inadequate nutritional care efforts on the part of the staff. This behavior is consistent with reports in the literature that family members may initiate and maintain a "hospital vigil", if they perceive that the patient is receiving sub-standard care (Welch, 1981).

That family members do evaluate care received by the patient has been reported in the empirical literature. Kristjanson's (1996) work documents that family members of palliative cancer patients look to health care providers to provide quality care to the patient. The provision of care that does not meet family expectations or leaves them with feelings of dissatisfaction and regret about the quality of care the patient received is reported to be stressful for family members. The finding in this study that some family members found the nutritional care of their dying relative wanting is troublesome, as it adds to the existing psychological and physiological changes individuals are known to experience in response to the stress of terminal illness in a family member (Cassileth, Lusk, Strouse, Miller, Brown, & Cross, 1985; Kristjanson, 1986; Oberst, Thomas, Gass, & Ward, 1989 Quinn & Herndon, 1986; Vachon, Fredman, Formo, Rogers, Lyall, and Freeman, 1977).

Research from the field of social psychology, specifically Klinger's Incentive-Disengagement theory (1975) and Wortman and Brehm's integrative model of psychological reactance (cited in Silver & Wortman, 1980) provide helpful theoretical contexts from which to understand "fighting-back" family behaviors described in this study. According the Klinger's Incentive-Disengagement theory, (1975) individuals respond to obstacles or to threatened loss of an important goal(s) or incentives with increased verve and vigor. When such responses do not facilitate the achievement of the incentive, individuals become increasingly angry and frustrated. Moreover, behavior becomes primitive and often more aggressive.

The description of behaviors and reactions associated with this part of the incentive-disengagement cycle is strikingly similar to the behaviors seen in family members who are entrenched in the fighting back mode of doing what's best. Acts of force-feeding in particular bear resemblance to the more primitive, aggressive behaviors identified in the model. Family members respond to patients' decreased intake of fluid and food and the possible impending death of the patient with considerable vigor. However, their concerted efforts invariably fail to produce the outcome or goal they desire, that is getting calories into the patient with the hope of prolonging the patient's life. When family member efforts were unsuccessful in achieving this goal, family members reported feelings of anger and frustration.

Letting Nature Take its Course: It's Best Not to Eat

The major conceptual category related to letting nature take its course was that of finding other ways to care that did not have food and feeding as their central focus. Family members who were letting nature take its course found other ways to care by participating in the patient's physical care, being there, and protecting.

Feeding has been characterized in the literature as a reciprocal act (Lynn, 1989). That is, the symbolic significance of feeding is rooted in the mutuality of giving to eat and drink, and of taking food and water" (Lynn, 1989 p. 87). Thus it may be argued that when the patient cannot or will not accept the gesture of feeding and watering, some families experience the act of feeding as "incomplete, useless, and arguably elective" (Lynn, 1989, p. 87). That some family members found the act of trying to feed and hydrate their dying relative of minimal import is supported by this research. These families had come to acknowledge the limitations of such interventions as hydration, and tube feeding in care of the dying. However, this does not mean, as was demonstrated in this study, that family members saw patients with declining intake as "beyond care". Indeed, the behaviors identified in this study associated with "finding other ways to care" are imbued with concern and compassion and are commensurate with those of "attending, abiding, not abandoning, and providing safe haven and safe passage", as described by Lynn (1989, p. 87).

For many family members in this study, finding other ways to care involved participation in the patient's physical care. Past research has also documented the importance of family involvement in the care of the patient during the terminal phases of illness (Harbeck, 1995; McClement & Degner, 1993; Degner, Gow & Thompson, 1991). Participation in care, for those who wish to do so, is believed to serve several functions. First, it may afford family members the opportunity to interact with the patient in highly satisfying ways in the remaining time that is left. Second, participation in the patient's care may help to validate the family members' expertise in this area. Family members frequently assume the responsibility of caring for patients with advanced disease in the home prior to admission to the hospital (Oberst, Gass, & Ward, 1989). As such, they often become very knowledgeable about the patient's needs, symptoms, and coping practices (Lobchuk, 1995).

Kristjanson's (1989a; 1989b) work examining family satisfaction with palliative care underscores the importance of health care providers valuing and respecting the caregiver's knowledge and expertise regarding the patient's care needs. Participation in care of the patient therefore provides families with the opportunity to share their perceptions and expertise with staff, and work collaboratively with them. Staff efforts to involve family members in the patient's care, and to respect family members for their roles as caregivers would thus appear to be an important activity (Avery, 1996; Welch, 1981).

An important activity for family members who were, "letting nature take its course" was that of "being there." This is consistent with reports in the literature suggesting that some family members have a need to "simply be" with the terminal cancer patient (Breu & Dracup, 1976; Haggmark, 1990 Lewandowski & Jones, 1988). Herth (1993) suggested that as the patient's physical health deteriorates, family members' sense of "doing" may be replaced with a more general sense of "being" with" their relative. This assertion was borne out in the actions of some family members in this study. However, as was also evident in this study, the act of being there was by no means a passive one.

The literature suggests that "being there" also affords the patient important opportunities. In their descriptive-exploratory study examining the most important concerns identified in a sample of terminally ill cancer patients (n=74), Geisinger and colleagues (1997) found that 97% of the sample indicated that is was very important to feel appreciated by their family; 95% to say good bye to the people closest to them; and 94% to be able to express their feelings to their family (94%). Arguably, it would be difficult, if not impossible, for terminal patients to accomplish any of these tasks when family caregivers are focused intently on getting the patient to eat.

Avery's (1996) ethnographic examination of bereaved family members' perceptions of care during the last 24 hours of the patient's life identified the importance of "being present" to family members. Her informants indicated that being with their dying relative was motivated by the need to observe care the patient received, and the need to ensure that the patient did not die alone. Family members also indicated that being with the patient was part of their responsibility that was borne out of love, respect, dedication, and the need to fulfill family roles. Moreover, Avery's (1996) respondents identified that their bereavement period would have been more difficult had they not spent time with their dying relative, and/or not witnessed their death.

There is evidence in the literature indicating that health care providers, notably nurses, perceive the importance of enabling the family to "be with the patient". This finding has been consistently documented in descriptive-exploratory research aimed at delineating expert nursing behaviors in care of the dying. A series of comparative qualitative studies examining expert models of nursing practice in the care of dying adults in palliative care units (Degner, Gow & Thompson, 1988) intensive care settings (McClement & Degner, 1993), medical wards (Harbeck, 1995) and in the community (Helwar, 1995) all identified the importance of nurses providing family members with opportunities to spend time with dying patients, should they wish to do so.

There is also literature to suggest that some terminally ill patients wish their relatives to be present with them during their illness experience and at the time of death (Keizer, 1992; Sykes, Pearson, & Chell, 1993). A common sentiment in these works is that some family member-patient dyads perceive that a "good death" was characterized, in part, by the patient being surrounded by loved ones.

Intervening Factors: Relationship to the Literature

Family member perceptions of causality regarding declining intake and weight loss

An unexpected finding in this study was that family members who were fighting back held the terminally ill patient, at least in part, responsible for the difficulties that they were experiencing with diminished intake and weight loss. That family members made such inferences about the causes of the patient's anorexia and cachexia, and judgements of responsibility about them is intriguing. To that end, attribution theory may provide a useful framework from which to begin to interpret this finding.

Broadly stated, attribution theory posits that an individual confronted with a threat or change in their environment will initiate a causal search in order to understand the reasons for the occurrence of the threat or change (Kelly, 1972 Weiner, 1995; Wong & Weiner, 1981). Attributional search is believed to be initiated in order to help the individual understand, predict, and control the change or threat (Kelley, 1972; Wortman, 1976). Micheala and Wood (1986) noted that the term attribution refers both to: i) the inferences that people make about states of being or causes of events; and ii) to whether or not an individual possess traits or dispositions to act in certain ways.

In the first phase of an attributional process, an individual faced with a particular outcome determines what caused that outcome. That is, causality is ascribed to a person or situation. If it is determined that there is situation causality, the motivational sequence stops. Conversely, if there is person causality the sequence continues. At the next phase of the process, wherein causality is allocated to the person, a determination is made as to whether the cause was controllable. The sequence halts in the face of uncontrollable causality, but proceeds in the face of controllable personal causality. The next phase of the sequence involves a search for mitigating factors or circumstances. In the presence of mitigating circumstances responsibility is not inferred (Weiner, 1995). However, the absence of mitigating circumstances in conjunction with perceptions of person causality and controllability, causality results in the inference of responsibility being made. Though presented in a linear sequence for purposes of clarity, a strict processing sequence should not be assumed. This is because judgements made initially may later be found to be incorrect or invalid in the presence of new information about the situation (Krull, 1993).

The responsibility process just described as conceptualized by Weiner (1995), has application to this study. The responsibility process is initiated by the events of declining intake of food and fluid and weight loss. If there is a judgement of personal causality, that is, if the family member perceives that the patient is the cause of these events then an inference of responsibility may be reached and the process continues. However, if the family member perceives impersonal causality, then a judgement of non-responsibility is rendered and the process stops. In the next step of the responsibility process, the family member will make a determination as to whether or not personal causality was controllable. If the family member perceives that the declining intake is caused by the patient, is intentional and controllable, and there are no circumstances to mitigate this, one would hypothesize, based on attribution theory, that family members then assign responsibility for the difficulties with decreased intake to the patient.

The literature suggests that a person's conception of how two or more causes combine to produce an effect, that is, their causal schema, influence the way in which people make causal attributions (Kelly, 1972). One causal schema, referred to as the discounting principle appears to have application to this study. The discounting principle posits that "the role of a given cause in producing a given effect is discounted if other plausible causes are also present (Kelly, 1972, p. 8). In this study, family members who were fighting back identified that illness-related factors impinged on the patient's appetite and subsequent intake. However, they also advanced the notion of the patient's personality as a factor operating in this regard. Thus, the role of disease related factors was somewhat discounted by family members in producing problems with intake, as other plausible causes (i.e. patient stubbornness or vindictiveness) were also present.

Family Perceptions Regarding Palliative Care

A troubling finding in this study is the perception on the part of some family members that "nothing is done" for patients when they are admitted to a palliative care unit. The issue of decreased public awareness regarding the focus and thrust of palliative care has been reported previously in the palliative care literature (Sellick, Dagsvik, & Kelley, 1996). Initial definitions of palliative appeared in the literature in the late 1970's (Saunders, 1978), and have briskly evolved over the past two decades (Kristjanson, 1997). That notwithstanding, the fact that palliative care constitutes active care and aggressive management of distressing symptoms in addition to attending to psychosocial needs and concerns appears to be foreign to the public (and indeed some health care providers not working in palliative care).

Information

Information was an important intervening factor in this study that influenced family member behavior regarding the nutritional care of their dying relative. Information included facts obtained through vigilant surveillance of the patient, auditing of the care delivered on the unit, and through interactions with family members of other patients. Information was also obtained from friends, relatives, and acquaintances. However, it appeared that the primary source of information for palliative care patients and their families were health care providers on the palliative care unit, and most often nurses. Through interactions with staff, family members were able to build an information base on which to interpret situations and make or revise decisions regarding the patient's care.

The importance of meeting the information needs of families experiencing a terminal illness has been well documented in the literature (Hampe, 1975; Freihofer & Felton, 1976; Wright & Dyck, 1984). Irwin and Meier's (1973) non-experimental study of the supportive care needs of families in terminal illness (n=20) indicated that families wanted health care providers "to be honest with me", to provide a clear explanation of what is being done for the patient and why, to keep family members informed, to show an interest in answering family questions. Families also wanted health care providers to ensure that their relative was kept comfortable.

Hampe's (1975) qualitative study examining the needs of grieving spouses (n=27) found that family members had eight areas of specific need. These areas included the need to: be with, and be helpful to their dying relative; to be assured that their dying

relative was comfortable; to be informed about the patient's condition and evidence of impending death; and the need for acceptance and support from health care providers.
the opportunity to ventilate feelings.

Research specifically examining the information needs of family members in palliative cancer care has been conducted by Kristjanson (1983; 1986; 1989a; 1989b). In a two-phase study, the researcher first had family members (n=33) identify health care provider behaviors that were most important to patient and family care. These items were then sorted by 210 families from three different care setting to identify the most salient indicators of quality care from a family perspective. Kristjanson found that five of the seven top-ranked family care items related to the need for information. Receiving honest, straight forward information from health care providers was the was ranked as being the most important family care need.

Receiving straightforward information did not always result in a change of family behavior. Even after some family members in this study had participated in ongoing discussions with health care providers about the causes of the patient's decline, and the benefits and burdens of particular interventions, behaviors associated with the fighting back sub-process of doing what's best frequently continued. For example, educating family members about the distinction between starvation in healthy individuals and the wasting that is seen in cancer cachexia did not always cause a change in "fighting back" behavior.

An issue that arose in conjunction with the importance of providing family members with information was the notion of trust. The presence of trust has been identified in the nursing literature as an important foundation from which to build rapport and therapeutic relationships with patients and families (Lynn-McHale, & Deatrick, 2000; Benoliel, 1976; 1985; Tornberg, McGrath, & Benoliel, 1984). In situations where families had been given information, but felt that they still lacked complete understanding, they put their trust in the health care provider to make the best decision and take the most appropriate course of action for the patient. Health care providers concurred that trust was an important element in their ability to be able to establish rapport with families. Moreover, the presence of a knowledgeable and competent caregiver who could communicate information about nutritional care to family members in a confident and caring manner went a long way in securing such trust.

Health care providers not working in palliative care were implicated in this study as providing family members with information about nutritional care in terminal illness that was either inaccurate or inappropriate, and thwarting the painstaking work that palliative care clinicians had done with families. Given that nurses and physicians typically receive minimal training in the principles and practice of palliative care during the course of their basic education, (Degner & Gow, 1988; Hill, 1995; Merman, Gunn, & Dickinson, 1991; Van Roenn, Cleeland, Gronin, Hatfield, & Pandya, 1993) this finding though troublesome, is not surprising.

Deficits in the management of symptoms commonly seen in advanced cancer patients by individuals without palliative care training is a prevalent problem (MacDonald, 1998a). There is little likelihood that such education is received by health care professionals even in post-graduate training programs. Sloan and colleagues (1997) recently examined the competency of residents graduating from a university general surgery training program regarding the management of common symptoms seen in advanced cancer patients. These researchers reported that the majority of physicians in the study (n=33) inappropriately managed lack of appetite in anorexic terminally ill cancer patients by using force feeding. It is little wonder that survey data frequently finds physician education and knowledge in palliative care to be inadequate, and patient outcomes to be "unacceptable" (MacDonald, 1998b;Von Roenn et al., 1993; MacDonald, Findlay, Bruera, Dudgeon, & Kramer, 1997; Vainio, 1995).

That families may seek out information about treatment options from individuals who might lack formal health training has been noted in the literature (Neuberger & Woods, 1995). Regarding this study, several family members reported that they used complimentary therapies based on the testimony of friends and neighbors, and/or the advice of alternative health care providers. The complimentary therapies embraced by patients in this study included the use of various diets, and vitamins, plant extracts, and immune therapies.

Individuals are believed to seek out such therapies for a variety of reasons. First, they may be frustrated with how their illness is being handled (Bennett & Lengacher, 1999; Neuberger & Woods, 1995). Second, they may believe that ordered treatment is inadequate in alleviating symptoms (Furnham & Smith, 1988). Montbriand and Laing (1991) contended that the act of exploring complimentary therapies may afford individuals who are frustrated and/or dissatisfied with more conventional treatment a sense of control and greater choice about the direction and emphasis of treatment. This latter assertion is supported by a recent study conducted by Sollner and colleagues (2000). Their survey findings of 172 patients undergoing active cancer treatment suggested that patients who use or are interested in complimentary therapies tend to do more information-seeking and problem-solving, behaviors characteristic of an active coping style.

Health care providers in this study raised several issues regarding the use of complimentary therapies. First, palliative care staff in this study felt that they had minimal information about the alternative therapies that patients and families used, and pointed to the need for evidence-based information about the efficacy of such therapies. Such evidence was seen as critical in order to be able to differentiate fraudulent treatment from more effective, worthwhile complimentary modalities. This perceived need for increased education about complimentary therapies is consistent with findings in other studies examining health care provider attitudes toward such therapies (Montbriand, 2000; Bourgeault et al., 1999).

Second, staff were worried that the desperation experienced by terminal cancer patients and their families made them very vulnerable to quackery and exploitation. The literature suggests that these concerns are, at least in part, well founded. "Quacks", that is, "individuals who promote medical schemes or remedies known to be false, or which are unproven" (Neuberger & Woods, 1995, p. 398) have historically promoted their treatments for their own profit (Martin et al., 1983). Moreover, the literature suggests that the amounts of money spent on complimentary therapies appears to be increasing (Downer et al., 1994; Eisenberg et al., 1994; Fletcher, 1992). It is understandable that the health care providers in this study were particularly concerned when they became aware that family members were required to assume a heavy financial burden in order to pay for certain treatments. While the staff interviewed for this study accepted the right of terminally ill cancer patients and family members to determine the treatment modalities that were the most meaningful for them, they did express the belief that some complimentary therapies, in addition to being ineffectual, were far more costly than traditional medical treatments.

Family members in this study also received information about care and treatment options through their interactions with other families on the palliative care unit. A qualitative study conducted by Harbeck (1995) examining nursing behaviors in care of the dying on adult medical units also identified that families often developed a support network with each other in which information is exchanged. There is evidence in the literature that family members are comforted when they are able to share their grief and concern with others who understand their situation (Kallenberg & Soderfeldt, 1992).

Experience

One of the important intervening conditions that influenced family members' responses to declining intake in their terminally ill relative was that of past experience. This finding is consistent with the literature examining the attributions of health and illness behavior, and the origins of hypothesis and beliefs about causes of symptoms. (Michela & Wood, 1986). That is, individuals may associate particular symptoms of an illness on the basis of past experience with that illness (Skelton & Pennebaker, 1982).

While health care providers may look to experiential knowledge as a basis for planning the care of dying patients, they more typically draw upon scientific knowledge as a basis for such care (Degner & Beaton, 1987). In contrast, family members typically do not have such knowledge and thus draw more on the experiential knowledge they have acquired. Such experience often comes as a result of lessons learned in caring for other family members or friends with terminal cancer. In this study for example, some family members reported that past experience had taught them about the futility of pushing food and fluid in dying persons. Other family members reported that based on past experience, they knew that some dying patients just "give up" when it comes to trying to eat, while others fight back and persevere.

Family members' past experience with their own hunger and thirst, may explain why some family members tended to project the uncomfortable sensations of hunger and thirst that they experience onto their dying relative. This act in turn fosters the notion that the patient who is not eating or drinking is suffering (Miller & Albright, 1989; Taylor, 1995). The natural corollary to this is that the patient's symptoms are not being well managed, hence the need to target the health care provider and petition for additional interventions.

The importance of managing symptoms in terminally ill patients has been documented in the literature (McClement, Woodgate, & Degner, 1997; Degner, Gow & Thompson, 1988). Indeed several authors have identified that family members who observe and witness a loved one's suffering may vicariously share that suffering (Battenfield, 1984; Gregory & English, 1994; Wilson, Balser, & Nashold, 1976).

That some family members in this study perceived their dying relative to be suffering due to lack of food and fluid is a significant issue, and underscores the need for family education and support in this regard.

Weighing the Burdens and Benefits

Regardless of which form "doing what's best takes", it is clear that family members engage in a process of weighing the burdens and benefits of what is done, or not done with respect to interventions related to nutritional care. It was clear from the data that an evaluation of the burdens and benefits regarding interventions related to nutrition and hydration were shaped and justified in part by an appeal to ethical principles. This is consistent with Kemp's (1999) assertion that certain fundamental ethical principles are brought into sharp focus where issues of end-of-life care are concerned.

Both family members who were “letting nature take its course” and “fighting back” advanced the ethical principles of beneficence, and nonmaleficence to support their respective positions. The principle of beneficence states that care should be provided that is in the patient's best interest (Kemp, 1999), while the principle of nonmaleficence posits that such care should not harm the patient (Dempsey & Dempsey, 2000). Families who were “letting nature take its course” felt that it was in the patients' best interest not to receive artificial nutrition or hydration, reasoning that such interventions might actually be harmful. Conversely, family members who were fighting back reasoned that it was in patients' best interest to receive nutritional support, and that harm would result if such intervention did not occur.

Two major differences in the ethical reasoning between families who were “fighting back” and those “letting nature take its course” were revealed in the findings.

First, it appeared that family members who were letting nature take its course placed great importance on the ethical principle of autonomy. The principle of autonomy states that the patient has a right to make his own decisions (Kemp, 1999). Thus, when patients indicated that they did not want to eat or receive any additional nutritional support, their decisions would be respected and their wishes honored.

In contrast, patient wishes, even when clearly stated, did not appear to be as readily honored by family members who were fighting back. This was most clearly evident in the behavior related to force-feeding. This discrepancy may be due to the second difference in ethical reasoning between the two extremes of doing what's best. That is, families who were "fighting back" tended to evoke the principle of sanctity of life when explaining their actions designed to increase intake. According to the principle of sanctity of life, life is sacred and should be preserved (Kemp, 1999). This principle appeared to be of such import that it allowed family members to usurp patient autonomy in order to obtain a more important outcome. One type of burden identified in the American literature (Zerwekh, 1997) as factoring into the balancing of burdens and benefits that was not identified in this study, concerned the financial burden that nutritional care interventions would pose for the family.

The findings from this study indicated that health care providers, while weighing the burdens and benefits of a particular treatment option also factored the social and emotional impact of their decision making on the family members of dying patients. That is, decisions about nutritional care were made and shaped, at least in part, for the sake of the family. This type of behavior has been reported previously in the context of research examining life-death decisions in health care, and is referred to as sentimental order calculation (Degner & Beaton, 1987). Degner and Beaton (1987) defined sentimental order as "a pattern of social and emotional functioning that maintains the stability of a group" (p. 58). Sentimental order calculation thus refers to the act of weighing the risks and benefits of different treatment options in terms of their impact on the sentimental order of the group (Degner & Beaton, 1987). This was illustrated most clearly in this study in the comments health care providers made regarding the "quasi-continuance " of an in situ intravenous line.

The inevitability of health care provider consideration of patient and family attitudes and feelings when making clinical decisions has been underscored by Mercadante (1995) who asserted that, "it is not possible to avoid the influence of the patient's and family's values, personal beliefs, and attitudes when making a decision about withholding or continuing nutritional support (p. 50). Consideration of such factors is consonant with what Duff (1987) has described as"close-up" ethics in health care. "Close-up" ethics refers to acknowledging the importance of feelings of patients and their families in addition to an appreciation of more abstract ethical principles. In contrast, distant ethics is described as the application of an ethical framework on individuals with minimal consideration of empathy. The health care providers in this study appeared to understand the warnings of Fainsinger and Gramlich (1997) who cautioned that palliative care clinicians who fail to practice close-up ethics in the course of decision making regarding nutritional interventions ....." run the risk of causing...severe psychological damage and hardship to the patient and family" (p. 51). From their perspective health care providers consistently indicated that it was ethically indefensible for their unit to have a blanket policy that advocated either providing or withholding artificial hydration or nutrition. Rather, it was important to take each patient situation on an individual basis, and evaluate the patient on a day to day basis.

The issue of IV hydration of palliative patients requires some additional comment. Health care providers in this study indicated that decision making regarding whether or not to hydrate is at best, an inexact science. This is due in large measure to the fact that little is known about the extent to which fluid volume status might cause or alleviate patient suffering. Viola and associates (1997) conducted a systematic review on the effects of fluid status and fluid therapy on the dying. The studies meeting the inclusion criteria for the review (n=6) were all descriptive, often lacked adequate description of the sample, and/or assessed only a limited range of outcomes relevant to the issue of hydration in the terminally ill (Viola, Wells, & Peterson, 1997). Given such limitations, the authors of the review appropriately conclude that, "it is impossible to draw firm conclusions regarding clinical care" (p. 50). Not surprisingly, there is a lack of consensus among palliative care clinicians regarding the effects of fluid therapy in palliative populations (Billings, 1985; Dunphy et al., 1995; Finlay Fainsinger & Bruera, 1994; Roberts, 1997).

The Symbolic Meaning of Food

The symbolic nature or meaning of food was identified as an important intervening factor in this study. Indeed, the finding that information alone is insufficient to evoke a change in family behavior suggests that such factors as the symbolic meanings family members assign to food and feeding influences their behavior related to nutritional care. Scanlon (1998) asserted that, "the language of food and water stirs deep emotion and is intrinsically linked to understandings of caring, compassion, and health" p. 141). To that end, foregoing medically provided nutrition and hydration is controversial and troubling precisely because of the deep symbolism associated with it (Chappelle, 1972; Leininger, 1988; Lupton, 1994).

The importance of the symbolic nature of food in relation to providing food and fluid both in terminal illness has also been identified in the literature. As such these writings provide a perspective from which to understand the family behavior related to nutritional care in terminal illness. Carson (1986) stressed that, "the simple act of offering to allay hunger and to slake the thirst of a dying person is deemed, across time and cultures to be not only right but good" (p.85). Beauchamp and Childress (1989) observe that "...denying food and water to anyone for any reason seems the antithesis of expressing care and compassion" (p. 166). Finally, Miles (1987) observed that "...feeding has a unique, morally decisive symbolic nature, signifying recognition of the humanity of vulnerable persons"...and is "the perfect symbol of the fact that human life is inescapably social and communal" (p. 295).

The symbolic nature accorded food identified in the literature is consistent with those expressed by family members in this study. That is, food appeared to carry biological and emotional meanings. From a biological perspective, family members saw food as providing nutrients essential for life. This perspective underpins family member assertions that their terminally ill relative will die without if they are not provided with a constant source of energy, and provides a rationale and justification to petition health care providers to intervene in the face of declining intake. From an emotional perspective, food symbolized love, caring, and nurturing.

While patients in this study identified that food served a necessary biological function, most did not see it fulfilling that function within the context of their illness. This was due in part to the fact that many patients experienced distressing symptoms when eating. Thus, such things as early satiety, bloating and nausea when taking in the very food that families deemed necessary for their survival. The majority of patients interviewed in this study did not speak of food as providing them with life-giving sustenance. More often than not, some of the negative consequences of ingesting such sustenance in their present state of health were evoked. This is consistent with the assertion made in the literature that food holds different meanings for use whether we are ill or well (Holmes, 1998; Gallagher-Allred, 1988).

Of interest is the finding that some of the family members in this study made a distinction about the importance of fluid versus food intake when difficulties eating and drinking became particularly profound. That is, the intake of fluid appeared to be linked in the minds of some family members as more important in ensuring survival. Meares (1997) reported a similar finding in her phenomenological study of caregiver experiences regarding intake cessation in terminal cancer patients. She reported that the caregivers in her study characterized food as "relational" and water as "functional", however, no further elaboration of these characterizations was provided.

Clearly, there are powerful inextricable links between caregiving and feeding.

Such links are so powerful McInerney (1992) suggested that, to the family members of dying patients, food and fluid are emotional symbols which may override rational thought. In like manner, Scanlon and Flemming (1989) noted that food "...has symbolic meaning that transcends the physical benefit it provides" (p. 982). The symbolism of food and fluids in this way helps to explain the resistance of some families to changing their behaviors and provides some insight into why they may engage in behaviors that lack efficacy and/or have the clear potential to harm patients.

The symbolic nature of food must also be appreciated with respect to its socio-cultural context. Food and eating symbolize interpersonal acceptance, friendliness, sociability, and warmth. Leininger's (1988) work has helped to articulate the symbolic meanings of food and their close linkages with cultural beliefs. However, there is minimal empirical literature examining the influence of culture on family attitudes toward the provision of food and fluid to terminally ill relatives. The work that does exist, however, demonstrates that food and the provision of nutrition are deeply laden with cultural meaning (Justice, 1995), and that culture is an important factor in shaping the responses of individuals regarding nutrition and hydration of the dying.

For example, Musgrave and colleagues (1996) examined the attitudes of Israeli terminal patients, families and health care providers regarding the use of intravenous hydration in terminal care. Though the sample sizes are small, the overall attitude toward IV fluids was reported as positive. The priority accorded the principle of the sanctity of life within the Jewish culture is advanced as the reason for this finding.

Justice (1995) conducted ethnographic research in India with an aim to examining the issues of sustenance at end-of-life. While he conceded that loss of appetite among dying people is common preceding death, he also argued that cessation among the dying Hindu peoples he observed was also culturally mediated. Specifically, cessation of eating was associated with a spiritually good death in that:

> "...when food has been foresaken, life leaves without a struggle. A struggle at the end is a very bad sign in terms of judging the fate of the soul...Not eating and drinking for some time before death probably results in a lowered chance of incontinence at the time of death...If there is incontinence at the time that the life's breath leaves the body, it indicates a bad fate....The cultural norms around which they are making decisions would be seen as allowing nature to take its course (p. 41-42).

The Consequences of Doing What's Best

The overall goal of family members, whether they be fighting back, letting nature take its course, or pseudo-surrendering, appeared to be that of reducing the potential for regret. Not being able to "do what was best" for the patient as perceived by the family member in terms of nutritional care, engendered guilt and distress in family members. The literature concerning bereavement guilt offers some insight to this aspect of the study's findings. While guilt is seen by many theorists as being a common and normal manifestation of grief (Lindemann, 1944; Bowlby, 1980), guilt that is excessive in intensity and duration is believed to be linked to poor bereavement outcomes (Miles & Demi, 1987). Minimal empirical work exists examining the sources of guilt feelings in the bereaved, and the associated variables influencing these feelings (Henslin, 1972; Miles & Demi, 1991). However, Demi and Miles' (1994) conceptual model of bereavement guilt appears to have application to some of the findings in this study.

Family members who were not able to provide or facilitate the nutritional care of their relative according to their perceived preference indicated that they felt guilty. This is similar to what Demi and Miles (1994) labeled as "illness-related guilt". In their model, illness-related guilt is defined as perceived failure in the caregiving role during the loved one's illness or at the time of death. Illness-related guilt may be expressed in such ways as perceived failure to adequately address symptoms and problems, regret for agreeing to further medical therapy and thus prolonging the loved one's suffering, and making medical decisions that have a negative effect of the patient's quality of life.

Demi and Miles (1994) also spoke of "relationship guilt" that results from a person's perceived failure to live up to self or societal expectations in their overall role with the dying person. This role may include both affective roles (e.g. giving and receiving affection) and instrumental roles (providing for nurturance and safety).When family members who feel that feeding is an important part of their role in relationship to the patient are unable to engage in this activity, they may experience guilt about not being able to fulfil the instrumental role of nurturer.

Study Limitations

Small sample sizes used in qualitative research such as the grounded theory study presented here often raise concerns about the issue of generalizability of the findings. However, it was not the researcher's intent to generalize, but rather to explore the range of issues related to nutritional care in the palliative care setting that emerged from the sample of patient, family, and health care providers interviewed in this study. That point notwithstanding, the following limitations are placed upon this study.

First, as is often the case in palliative care research sampling family members, women were over-represented in this study. The perspectives of men caring for their anorexic cachectic relatives and partners may well be different from those of women caregivers, and need to be examined. Data from this group may provide additional facets to the preliminary model that has emerged from this study.

Second, as is often the case in palliative care research in general, the sample recruited for this study is not representative of Canada's cultural diversity. Canada's changing population and influx of immigrants makes it "a rich tapestry of cultures from around the world" (Hall, Stone, & Fiset, 1998, p. 46). However, given that ethnic minorities are under-represented in this sample, the cultural relevance of the model that has emerged from the study is unknown.

Third, the data collected for this study was generated from patients, families, and health care providers who were experiencing care in an exemplary palliative care setting. However, the vast majority of palliative cancer patients and their family members are cared for on hospital medical-surgical units that may espouse an ethos that is different from that found on a palliative care unit. Therefore, the extent to which the framework of understanding that emerged in this study might have utility in other care contexts is unknown.

Recommendations for Future Research

The findings of the present study suggest the need for further research.

1. This study has generated a preliminary model from which to understand nutritional care issues relative to the palliative care context. In order to assess the usefulness of the model, this study needs to be replicated with patients, families and

health care providers in different end stage disease groups (e.g. end stage kidney failure and heart failure), receiving care in a variety of contexts (e.g. medical-surgical units, and the community).

2. The finding that family members who adopt a "fighting back" approach also tended to hold the terminally ill individual responsible, at least in part, for their declining health warrants closer examination. Evidence from the present study suggests family members engage in causal search and attribution to understand patient problems with nutritional intake. Further research is needed to validate this finding with an aim to examining when in the illness trajectory attributions are made, and whether or not causal attributions co-vary with the stage of disease.

3. The findings from the study suggest that families need to receive information from palliative care clinicians regarding the causes of decreased appetite and weight loss, the normalcy of such events, and the burdens and benefits of nutritional interventions. These factors constitute a preliminary list of information needs related to nutritional care. However, given that a delineation of information needs was not the focus of this study, that list may be incomplete. Research aimed at identifying and describing the precise information needs related to nutritional care needed by families is indicated. Such work could provide the foundation for intervention studies designed to examine the most effective ways of teaching families members about issues related to nutritional care in the terminally ill.

4. Cohen and colleagues (1996) asserted that cultural responses to death and dying may take on increased importance once interventions aimed at cure have failed.

The findings from this study indicate that different cultural groups may have diverse perceptions about the role of food and fluid in palliative cancer care, thereby underscoring the importance of culture as a mediating influence regarding family member attitudes toward the provision of food and intravenous fluids to terminally ill cancer patients. Future research accessing the perspectives of individuals from a variety of cultures regarding the issue of nutritional care in advance disease is thus warranted.

5. The findings of this study suggest that physicians and nurses may, on occasion, hold disparate views regarding what constitutes appropriate nutritional intervention for dying patients. This may be a function of differences in ethical reasoning. Much of the extant ethical literature regarding nutritional care discusses the way that health care providers should reason. This is not necessarily analogous to the ways they actually do reason. To that end, further research examining the ethical reasoning of nurses and physicians in the area of nutritional care of terminal cancer patients might be a fruitful area of inquiry.

6. Findings from this study suggest that the experience of unintentional weight loss and altered body image associated with the cancer-anorexia-cachexia syndrome poses a significant psychological stressor for some terminal cancer patients. While it is acknowledged in the literature that cancer and AIDS-induced cachexia has considerable impact on the patient's body image (Bruera & Fainsinger, 1995; Hopwood, 1992), and has implications for the ways in which social encounters are managed (Price, 2000) little is actually known about this experience from the patient's perspective. It will not be possible to eradicate the underlying cause of the cachexia in this patient population.

However, descriptive exploratory work with cachectic cancer patients may provide insights and direction regarding a potentially useful psychotherapeutic intervention aimed at helping to alleviate the distress associated with changing body image secondary to cancer cachexia.

Recommendations for Practice & Education

The findings from this study have implications for practicing clinicians and educators.

1. First, this study underscores the importance of responding to family anger around what they may perceive to be as a lack of caring and compassion on the part of health care providers when aggressive nutritional interventions are not implemented. This is a critical first step if the underlying issues fueling behavior related to force-feeding and targeting of the health care provider are to be adequately addressed. Students and practicing clinicians need to be taught the importance of engaging in empathic communication with family members in this regard.

2. Secondly, not all family members may be aware that anorexia-cachexia are manifestations of end stage disease, and that intake cessation in the last days of life are a normal and expected event. The importance of teaching family members about what to expect, however obvious to clinicians, cannot be understated.

3. Third, health care providers need to explore with family members their perceptions of causality related to the patient's nutritional difficulties. This may uncover attributions related to blaming the patient, and provide an inroad from which to begin to correct misinformation, and engage in collaborative goal setting regarding the patient's

care.

4. Fourth, it was clear from health care providers that interacting with families regarding the issue of nutritional care in the palliative care setting is a complex and emotive issue. The perceived importance of collegial support in dealing with this issue was a recurrent theme in interviews with health care providers. There is clearly a need for both formal and informal ways in which members of the health care team can debrief with one another regarding the ways in which the patient's plan of care is crafted and implemented.

5. Fifth, it is evident that palliative care has an image problem!! Clinicians need to be aware that families may harbor concerns that nothing will be done for their dying relative once they are admitted to the palliative care unit, and that such concerns may, at least in part, be driving requests for nutritional intervention. This finding also underscores the need to educate both family members and the public regarding the goals and aims of palliative care.

6. Palliative care is frequently delivered not on units with dedicated palliative care beds, but on acute medical-surgical units. The findings from this study indicate that family members make comparisons between the amount and type of intervention their relative receives in comparison to other patients on the same unit. Clinicians working on mixed units, that is units housing both palliative and non-palliative patients need to take special care to explain these apparent "discrepancies" to families.

7. Seventh, the findings of the study stress the importance of clinicians, particularly nurses, taking the time and effort to model care behaviors that family

stance to a letting nature take its course position.

8. Health care providers working in palliative care identified a lack of knowledge regarding the principles, goals, and aims of palliative care on the part of many of their colleagues working in other specialities. This points to the need for palliative care education for medical and nursing colleagues who do not work on units with dedicated palliative care beds, but who nevertheless may be charged with the responsibility of providing care to terminally ill individuals. Ideally, such education should be part of basic undergraduate education.

9. Finally, certain family characteristics were postulated in this study as being influential in shaping family member responses regarding "doing what's best. This suggests that health care providers carefully assess family interaction patterns and characteristics with an aim to identifying potential stresses in these interactions.

Conclusion

This work has resulted in the generation of a preliminary model related to the ways in which family members of palliative cancer patients manage the means and goals of nutritional care, while meeting their own needs related to the provision of this care. The involvement of key stakeholders (i.e. patients, families, and health care providers) in the generation of data from which the model emerged has formed the basis for the development of a substantive theoretical model related to nutritional care in the palliative care setting. The delineation of this model provides the foundation from which future description and testing of relationships among variables related to this issue might take place, and an empirical stance from which to consider intervention studies to alleviate description and testing of relationships among variables related to this issue might take place, and an empirical stance from which to consider intervention studies to alleviate sources of conflict related to differences in perceptions between patients, families, and health care providers about the role of nutritional intervention in palliative cancer care.

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APPENDIX A

REQUEST TO RELEASE PATIENT NAME TO RESEARCHER

(To be used by Clinical Resource Nurse of the Palliative Care Unit)

Susan McClement is a nurse and a doctoral student at the University of Manitoba. She is doing a study to learn about the nutritional care people with cancer receive in the hospital. Any information you might choose to share with the researcher is confidential. Whether or not you decide to participate in the study will in no way affect the care you receive on the Palliative Care Unit.

Susan would like to talk to you to tell you more about the study and invite you to participate. Would it be alright with you if I gave her your name so she can come and talk to you directly and explain the study.

(If agreeable, the name of the patient is given to the researcher and the Clinical Resource Nurse thanks the individual. If the patient declines, the nurse thanks the patient for their time).

APPENDIX B

PATIENT CONSENT FORM

Nutritional Care in Advanced Cancer: The Experience of Patients, Families, and Health Care Providers

I ______________________________ agree to participate in the above titled research project. The purpose of the study is to gain an understanding of the experiences of patients, families and health care providers regarding the nutritional care of cancer patients in the advanced phases of illness. The study is being conducted by Susan McClement, a doctoral student from the University of Manitoba. The study has been approved by the Ethical Review Committees of the University of Manitoba, and St. Boniface General Hospital.

I understand that my signature below indicates only that I agree to participate in the study and allow the investigator access to my chart to gather information about the care I am receiving. I also understand that my involvement in the study will include participating in an interview with the researcher while I am in hospital. The interview will take approximately 1 hour. My participation is voluntary and I may withdraw from the study at any time by simply telling the researcher. If i feel tired and wish to stop the interview, or prefer to continue at a different time, that is fine. My decision to participate or not participate in the study will in no way affect the care I receive on the unit.

The information I provide will be confidential. My name will not be used in any reports about the study and only a report of grouped information will be provided to the hospital. Results from the study may be published.

Answering some questions may arouse sad feelings about my illness. Otherwise, there are no known risks involved in participating in the study. The study offers no direct benefits to me. However, the results may be helpful to health care professionals (like nurses and doctors) caring for cancer patients and their families by giving them information about how to improve the care they give.

I understand that I can receive answers to any questions about the study at any time. I understand that Susan can be reached at 235-3480 if I have further questions about the study. Susan's research advisor is Dr. Lesley Degner (235-3483) in the Faculty of Nursing at the University of Manitoba.

I agree to participate in this project.

Your signature______________________________ Date__________________

Interviewer__________________________________ Date___________________

APPENDIX C

REQUEST TO RELEASE FAMILY MEMBER NAME TO RESEARCHER

(To be used by the Clinical Resource Nurse of the Palliative Care Unit)

Susan McClement is a nurse and a doctoral student at the university of Manitoba. She is doing a study to learn about the nutritional care people with cancer receive in the hospital. Any information you might choose to share with the researcher is confidential. Whether or not you decide to participate in the study will in no way affect the care your family member will receive on the palliative care unit.

Susan would like to talk to you to tell you more about the study and invite you to participate. Would it be alright with you if I gave her your name and/or phone number so she can come and talk to you on the unit or telephone you directly to explain the study?

(If agreeable, the name of the family member is given to the researcher and the Clinical Resource Nurse thanks the individual. If the family member declines, the nurse thanks the person for their time).

APPENDIX D

CONSENT FORM FOR FAMILY MEMBERS

Nutritional Care in Advanced Cancer: Experiences of Patients, Families, and Health Care Providers

I ______________________________ agree to participate in the above titled research project. The purpose of the study is to gain an understanding of the experiences of patients, families and health care providers regarding the nutritional care of cancer patients in the advanced phases of illness. The study is being conducted by Susan McClement, a doctoral student from the University of Manitoba. The study has been approved by the Ethical Review Committees of the University of Manitoba, and St. Boniface General Hospital.

I understand that my participation involves participating in an interview with the researcher and will take approximately 1 to 1 ½ hours. The researcher will ask me questions about my experiences with nutritional support in the care of my family member who is a patient on the palliative care unit. The interview will be tape-recorded to allow the researcher to listen carefully to me. The tapes will by typed out later by the researcher. Names mentioned on the tapes will be replaced by pretend names so that the typed information will be confidential. Only a report of group information will be provided to the hospital. Results of the study may be published.

The interview will occur in a place convenient to me and the researcher, such as my home. My participation is voluntary and I may withdraw from the study at any time by simply telling the researcher. If I feel tired and wish to stop the interview, or would prefer to continue at a different time, that is fine. My decision to participate, or not participate in the study will in no way affect the care my family member receives.

Answering some questions may arouse sad feelings about my family member's illness. Otherwise, there are no known risks involved in participating in the study. The study offers no direct benefits to me. However, the results may be helpful to health care professionals caring for cancer patients and their families by giving them information about how to improve the are they give.

I can receive answers to questions about the study at any time. I understand that Susan can be called at 235-3480, if I have any further questions about the study. Her research advisor is Dr. Lesley Degner, Faculty of Nursing, University of Manitoba (235-3482).

I agree to participate in this project.

Your signature________________________________ Date_____________

Interviewer__________________________________ Date_____________

✂...

I would like a summary report of the findings: (Please check one)

Yes____ **No____**

Please mail a summary of the report findings to:

Name:_________________________________

Address:_______________________________

Postal Code:____________________________

APPENDIX E

REQUEST TO RELEASE BEREAVED FAMILY MEMBER NAME TO RESEARCHER

(To be used by the Clinical Nurse Specialist of the Palliative Care Unit)

Susan McClement is a nurse and a doctoral student at the University of Manitoba. She is doing a study to learn about the nutritional care people with cancer receive in the hospital from the perspective of family members who have experience with this topic. Any information you might choose to share with the researcher is confidential. You are in no way obliged to participate in the study.

Susan would like to talk to you to tell you more about the study and invite you to participate. Would it be alright with you if I gave her your name and phone number so she can telephone you directly and explain the study?

(If agreeable, the name of the bereaved family member is given to the researcher and the Clinical Nurse Specialist thanks the person for their time).

APPENDIX F

CONSENT FORM FOR BEREAVED FAMILY MEMBERS

Nutritional Care in Advanced Cancer: Experiences of Patients, Families, and Health Care Providers

I ________________________________ agree to participate in the above titled research project. The purpose of the study is to gain an understanding of the experiences of patients, families and health care providers regarding the nutritional care of cancer patients in the advanced phases of illness. The study is being conducted by Susan McClement, a doctoral student from the University of Manitoba. The study has been approved by the Ethical Review Committees of the University of Manitoba, and St. Boniface General Hospital.

I understand that my participation involves participating in an interview with the researcher and will take approximately 1 to 1 ½ hours. The researcher will ask me questions about my experiences with nutritional support in the care of my family member who was a patient on the palliative care unit. The interview will be tape-recorded to allow the researcher to listen carefully to me. The tapes will by typed out later by the researcher. Names mentioned on the tapes will be replaced by pretend names so that the typed information will be confidential. Only a report of group information will be provided to the hospital. Results of the study may be published.

The interview will occur in a place convenient to me and the researcher, such as my home. My participation is voluntary and I may withdraw from the study at any time by simply telling the researcher. If I feel tired and wish to stop the interview, or would prefer to continue at a different time, that is fine.

Answering some questions may arouse sad feelings as I think back about my family member's illness. Otherwise, there are no known risks involved in participating in the study. The study offers no direct benefits to me. However, the results may be helpful to health care professionals caring for cancer patients and their families by giving them information about how to improve the care they give.

I can receive answers to questions about the study at any time. I understand that Susan can be called at 235-3480, if I have any further questions about the study. Her research advisor is Dr. Lesley Degner, Faculty of Nursing, University of Manitoba (235-3482).

I agree to participate in this project.

Your signature______________________________ Date_____________

Interviewer_________________________________ Date_____________

✂ ....

I would like a summary report of the findings: (Please check one)

Yes____ **No____**

Please mail a summary of the report findings to:

Name:________________________________

Address:______________________________

Postal Code:___________________________

APPENDIX G

DISCLAIMER FOR HEALTH CARE PROVIDERS

You are being asked to voluntarily participate in a study entitled, "Nutritional Care in Advanced Cancer: The Experiences of Patients, Families, and Health Care Providers."

The purpose of the study is to learn about the experiences of patients, families, and health care providers regarding the nutritional care of advanced cancer patients. The study is the focus of my dissertation and is part of my graduate work in the Interdisciplinary Doctoral Program at the University of Manitoba. My supervisor is Dr. Lesley Degner, Professor, Faculty of Nursing at the University of Manitoba. The study has been approved by the Ethical Review Committees of the Faculty of Nursing, University of Manitoba, and St. Boniface General Hospital.

Your participation in the study would mean that I would be observing you while you participate in interdisciplinary rounds and/or death reviews. I may also ask you questions during or after the observation period. Observations and questions would relate to issues concerning nutritional care in advanced cancer patients. All observations would be as unobtrusive as possible and would not interfere with your activities. Also, if a situation arises wherein you would prefer I not record what you are saying or doing, I will respect your request. By allowing me to observe you and responding to my questions, you are consenting to participate in the study.

The decision to participate is entirely your own. If you do not wish to participate, it will not affect your employment status with the hospital. It is not expected that the study will produce any direct benefits to the staff who participate. However, the study may produce some valuable information that will help health car providers in the future understand issues related to nutritional care in advanced cancer.

All information collected is for the purposes of my dissertation, and in no way constitutes an evaluation of your work performance. The results may be published in the future. In both instances, you identity would not be revealed to anyone. Observation and interview data will be identified by code number only.

If you have any questions about the study, you me contact me at 475-5087. Dr. Degner can be contacted at 235-3480.

Thank you very much for your consideration of this project.

APPENDIX H

CONSENT FOR HEALTH CARE PROVIDERS

As a health care provider working on a palliative care unit, you are being invited to participate in the above titled research project. The purpose of the study is to learn about the experiences of patients, families, and health care providers regarding the nutritional care of advanced cancer patients. The study is being conducted by Susan McClement, a nurse and doctoral student at the University of Manitoba.

You will be asked to participate in an interview lasting approximately one hour. The researcher will ask you some questions about your thoughts and experiences concerning the role of food and fluid in terminal cancer care. The interview will be tape-recorded to allow the researcher to listen carefully to you. The tapes will be typed out later by the researcher. Names mentioned on the tape will be replaced by fictional names.

The interview will occur at a place convenient to you and the research nurse, such as your own home. The interview may be stopped at any time if you choose. The researcher may make a few brief notes during the interview. You will also be asked to fill out a short questionnaire about yourself (e.g. age, years of experience in palliative care). This form should take less than 5 minutes to complete. Consent forms, tapes, and questionnaires will be kept separately in locked filing cabinets in the researcher's' office.

The information collected from you during the interview will be kept confidential. Findings from the study may be published. Reports of the study will not include names, and only grouped information will be used.

The study poses no known risks to you. However, some individuals may experience a stirring of emotion as they discuss their experiences dealing with patients and families for whom issues of food and fluid were particularly troublesome. The study offers no direct benefits to you. However, people who participate in these types of interviews often say they feel a little better after the interview because of the chance to share their views about challenging clinical situations.

You are welcome to receive answers to any questions about the study any time, by calling Susan at 235-3480. If you wish to contact my advisor for the study, Dr. Lesley Degner, Professor in the Faculty of Nursing at the University of Manitoba, please call 235-3482.

I agree to participate in this project.

Your signature______________________________ Date______________

Interviewer_________________________________ Date______________

✂……………………………………………………………………………………

I would like a summary report of the findings: (Please check one)

Yes____ **No____**

Please mail a summary of the report findings to:

Name:__________________________________

Address:________________________________

Postal Code:_____________________________

APPENDIX I

PATIENT INTERVIEW GUIDE

1. Tell me about your illness, and how it affected your appetite and/or ability to eat when you were at home.

probe-->concerned over loss of appetite? What did this signify? Reactions of patient? Of family?

probe-->who made decisions about how much and what you ate at home? Areas of disagreement about this with family members?

probe--> family members concerned when you don't eat or drink as much as they think you should?

2. Tell me how your appetite has been since you have been in hospital.

probe-->concerned about appetite/level of intake?

probe-->concerned if doesn't eat but drinks?

probe-->feel hungry or thirsty? What helps?

probe-->staff talk to you about effect of illness on appetite? Encourage you to eat or drink?

probe-->Patient response to discussion/encouragement, or lack thereof?

probe--> Role patient wants to play in deciding about what to eat and drink in hospital?

APPENDIX J

FAMILY INTERVIEW GUIDE

1. Tell me about (insert patient's name) illness, and how it has affected his/her appetite and/or ability to eat while at home.

probe--> what concerns family member the most when patient doesn't eat or drink as much as they think he/she should?

probe--> actions taken by family with regard to patient's nutritional intake?

probe--> reaction of patient to family actions taken regarding nutritional intake?

2. Tell me how (insert patient's name) appetite has been while in hospital.

probe--> actions taken by family with regard to nutritional intake when patient is in hospital (i.e. initiate discussions with staff; bring in food from home)

probe--> desire to be involved in decision-making about nutritional care of patient?

probe--> actions taken by staff in regard to nutritional care of patient (i.e. talk to patient and family about nutritional care? special type of diet ordered?)

probe-->family perceptions of actions taken by staff in regard to nutritional care of the patient

probe---> concerned patient will feel hunger or thirst?

probe--> more concerned if patient doesn't eat but drinks?

4. Is there anything else you would like to tell me about your family member's illness as it relates to nutrition that we haven't talked about yet?

**If more than one family member per patient is identified, and/or if additional family members apart from the one identified by the patient are interested in participating in the study, multiple family members will be recruited. In the event that more than one family member would like to participate in the study, family members will be given a choice about whether they prefer an individual or group interview with the other family member. For those who opt for a joint interview, they will also be given an opportunity for individual follow-up time with the researcher in the event that there are additional perspectives that they might wish to share privately. This will apply to bereaved families as well.

APPENDIX K

BEREAVED FAMILY MEMBER INTERVIEW GUIDE

1. Tell me about your family member's illness, and how it affected his/her appetite and/or ability to eat when they were at home, prior to going to the hospital.

probe--> actions taken by family with regard to patient's nutritional intake

probe--> reaction of patient to family actions taken regarding nutritional intake

2. Tell me how your family member's appetite was while they were in the hospital before they passed away.

probe--> actions taken by family with regard to nutritional intake when patient is in hospital

probe--> actions taken by staff in regard to nutrition

probe--> perceptions of family to actions taken by staff in regard to nutrition

3. What concerned you the most when your family member didn't eat or drink as much as you thought they should?

probe---> concerned patient felt hunger or thirst?

probe--> more concerned if patient didn't eat but drank?

4. Based on your experience, what would you tell other families who are concerned about the fact that their family member with cancer isn't eating or drinking as much as they would like them to?

5. Based on your experience, what things did hospital staff say or do that were helpful to you when you were worried that your family member wasn't eating or drinking as much as you would have liked them to? What things were not helpful?

--> help from sources other than staff (i.e. other families on PCU)

4. Is there anything else you would like to tell me about your family member's illness as it relates to nutrition that we haven't talked about yet?

APPENDIX L

HEALTH CARE PROVIDER INTERVIEW GUIDE

1. From your experience in palliative care, what type of nutritional care do you think is most appropriate for advanced cancer patients in the terminal phases of illness?

probe-->what guides your decision-making about nutritional care in terminal illness? (i.e. National Guidelines? Risk-benefit? Ward Policy? Research literature?)

probe--> do you believe patients and family members share this perspective? If not, how do their perspectives differ? What underlies their point of view about nutritional care?

probe--> in your experience, how much do you think patients want to be involved in making decisions about their nutritional care? Families?

probe-->are patients/families included in decisions about nutritional care? How?

2. What do you think concerns families the most when their terminally ill relative doesn't eat or drink as much as family members think they should?

probe---> families concerned patient felt hunger or thirst?

probe--> families more concerned if patient didn't eat but drank?
probe-->do you see artificial hydration (i.e. intravenous fluids or hypodermoclysis) playing a role in the nutritional care of advanced cancer patients? Do you think patients and families see it as such?

3. Please tell me about a case in which nutritional care issues were particularly challenging.

probe-->what made it challenging? Common features of a challenging case?

probe-->actions taken? What works? What doesn't? How to avoid pitfalls?

probe-->issue of patient abandonment if artificially provided food and fluid not offered? Feel compelled to use available technology?

probe--> concerned patient hungry or thirsty if artificially provided food and fluid not offered

APPENDIX M

ID#___

PATIENT DEMOGRAPHIC FORM

1. Marital status: Married ___ Never married___ Common-law___
Divorced ___ Widowed ___

2. Age: 18-30 years ___ 51-65 years ___
31-50 years ___ over 65 years ___

3. Gender: male ___ female ___

4. Education: grade 8 or less ___ some college ___
some high school ___ college degree ___
high school diploma ___ graduate degree ___

5. Occupation: clerical ___ retired ___ homemaker___ labourer ___
professional___ retail___ management ___ other___

6. Family Income:
below $10,000/year ____
$11,000-$20,000/year ___
$21,000-$30,000/year ___
$31,000-$40,000/year ___
$41,000-$50,000/year ___
$51,000-$60,000/year ___
$61,000-$71,000/year ___
over $70,000/year ___

7. Ethnic Background: European ___ Aboriginal peoples ___
British Isles ___ Asian ___
French ___ Other ___

8. Religion: Catholic ___ Protestant ___ Jewish ___
Other ___ None ___

9. Patient's Diagnosis (Primary) ____________________

10. Stage of Disease: III ___ IV ___

c. Kristjanson, 1992

APPENDIX N

ID#___

IN-PATIENT FAMILY MEMBER DEMOGRAPHIC FORM

1. Marital status: Married ___ Never married___ Common-law___
Divorced ___ Widowed ___

2. Age: 18-30 years ___ 51-65 years ___
31-50 years ___ over 65 years ___

3. Gender: male ___ female ___

4. Relationship: spouse ___ son ___ daughter ___
to patient: sibling ___ other_____(specify)

5. Education: grade 8 or less ___ some college ___
some high school ___ college degree ___
high school diploma ___ graduate degree ___

5. Occupation: clerical ___ retired ___ homemaker ___
labourer ___ management ___ other ___
retail ___ professional ___

6. Family Income:
below $10,000/year ____
$11,000-$20,000/year ___
$21,000-$30,000/year ___
$31,000-$40,000/year ___
$41,000-$50,000/year ___
$51,000-$60,000/year ___
$61,000-$71,000/year ___
over $70,000/year ___

7. Ethnic Background: European ___ Aboriginal peoples ___
British Isles ___ Asian ___
French ___ Other ___

8. Religion: Catholic ___ Protestant ___ Jewish ___
Other ___ None ___

APPENDIX O

ID#___

BEREAVED FAMILY MEMBER DEMOGRAPHIC FORM

1. Marital status: Married ___ Never married___ Common-law___
Divorced ___ Widowed ___

2. Age: 18-30 years ___ 51-65 years ___
31-50 years ___ over 65 years ___

3. Gender: male ___ female ___

4. Relationship to patient: spouse ___ son ___ daughter ___
sibling ___ other ___(specify)

5. Education: grade 8 or less ___ some college ___
some high school ___ college degree ___
high school diploma ___ graduate degree ___

6. Occupation: clerical ___ retired ___ homemaker ___
labourer ___ management ___ other ___
retail ___ professional ___

7. Family Income: below $10,000/year ____
$11,000-$20,000/year ___
$21,000-$30,000/year ___
$31,000-$40,000/year ___
$41,000-$50,000/year ___
$51,000-$60,000/year ___
$61,000-$71,000/year ___
over $70,000/year ___

8. Ethnic Background: European ___ Aboriginal peoples ___
British Isles ___ Asian ___
French ___ Other ___

9. Religion: Catholic ___ Protestant ___ Jewish ___
Other ___ None ___

10. Patient's diagnosis (primary): ____________________

11. Length of time since patient's death:* __________________
*Information to be collected from Liaison Nurse on PCU

APPENDIX P

ID#___

HEALTH CARE PROVIDER DEMOGRAPHIC FORM

1. Marital status: Married ___ Never married___ Common-law___
Divorced ___ Widowed ___

2. Age: 18-30 years ___ 51-65 years ___
31-50 years ___ over 65 years ___

3. Gender: male ___ female ___

4. Education: grade 8 or less ___ some college ___
some high school ___ college degree ___
high school diploma ___ graduate degree ___

5. Position on Palliative Care Unit

registered nurse__ chaplain___

unit assistant___ social worker___

physiotherapist___ occupational therapist___

physician___ other_____(specify)

6. Years of experience
working in palliative care ______________

7. Ethnic Background: European ___ Aboriginal peoples ___
British Isles ___ Asian ___
French ___ Other ___(specify)

8. Religion: Catholic ___ Protestant ___ Jewish ___
Other ___ None ___

APPENDIX Q

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#97/21

Proposal Title: "NUTRITIONAL CARE IN ADVANCED CANCER: THE EXPERIENCES OF PATIENTS, FAMILIES, AND HEALTH CARE PROVIDERS."

Name and Title of Researcher(s):
SUSAN McCLEMENT, RN, PhD(C)
INTERDISCIPLINARY DOCTORAL STUDENT
FACULTY OF GRADUATE STUDIES
UNIVERSITY OF MANITOBA.

Date of Review: JUNE 02, 1997.

APPROVED BY THE COMMITTEE: JUNE 17, 1997.

Comments: APPROVED WITH CHANGES SUBMITTED JUNE 10TH, 1997.

Date: JUNE 17, 1997.

Karen Chalmers

Karen L Chalmers, PhD, RN
Associate Professor
University of Manitoba Faculty of Nursing

Chairperson

Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se