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A NECESSARY EVIL? PATIENTS' EXPERIENCES WITH TUBE FEEDING IN ACUTE CARE

BY

CARA GREEN

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Submitted by

Cara Green

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The thesis examination committee certifies that the thesis
and the oral examination is approved

Supervisor:

Dr. Virgina Walker
Athabasca University

Committee members:

Dr. Sharon Moore
Athabasca University

Dr. Debbie MacLellan
University of Prince Edward Island

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Dedication

This thesis is dedicated with love and admiration to Trina, whose strength and courage provided the impetus to extend my knowledge, and who remains my inspiration in life.

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Abstract

Tube feeding (TF) for adults admitted to acute care is frequently prescribed for managing malnutrition, yet little is known about patients' experiences receiving this therapy, including their information and support needs. Based on an Interpretive Description approach, 12 unstructured interviews were conducted with participants admitted to acute care hospitals in Canada. Findings revealed variations in participants' perceptions about the ***NECESSITY*** for TF and the ***DISCOMFORT*** resulting from this therapy that were influenced by the inter-related themes: a) the additional ***Meaning*** of TF, b) the ***Trust*** held in Dietitians and Health Care Providers, and c) participant ***Resilience***. Collectively, these findings are subsumed within a central theme phrased as a question about the experience of TF as: ***A NECESSARY EVIL?*** Participants' answers to this question influenced their engagement throughout TF therapy. The range of responses and the complexity of patients' experiences during TF necessitate that Dietitians be supportive and flexible, applying a patient-centered approach to care.

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CHAPTER 1

INTRODUCTION

Being hospitalized for an acute illness is a highly stressful event that for many adult patients requires invasive and uncomfortable therapies such as tube feeding (TF). Tube feeding (TF) is a relatively common, standard therapy in Canadian hospitals, and usually impermanent, for specific clinical conditions to prevent or ameliorate malnutrition (Brantley & Mills, 2012; Heyland, MacDonald, Keefe, & Drover, 1998). Tube feeding is known to cause hospitalized patients considerable physical and psychosensory distress (Bruning et al., 1988; Padilla et al., 1979) that may be compounded by the emotional and social consequences of being unable to eat (Winkler, 2007). Indeed, the substantial body of literature-examining patients living with TF at home, has provided a rich description of the positive and negative impacts that TF, and being unable to eat, has on their quality of life and their need for information and support (Bannerman, Pendlebury, Philips, & Subrata, 2000; Brotherton & Abbott, 2009; Brotherton, Abbott, & Aggett, 2006; Jordan, Philpin, Warring, Cheung, & Williams, 2006; Mayre-Chilton, Talwar, & Goff, 2011; Osborne, Collin, Posluns, Stokes, & Vandenbussche, 2012; Rickman, 1998; Senft, Fietkau, Iro, Sailer, & Sauer, 1993; Verhoef & Van Rosendaal, 2001; Walker, 2005). However, how patients admitted to a general hospital ward describe their experiences and needs with respect to impermanent TF remains unknown. Researchers have demonstrated that the hospitalized patient’s discomforts with TF may be misunderstood by health care providers and that, unsurprisingly, TF carries a stigma among hospitalized and nursing home patients (Keyser-Jones, 1990; Scolapio, Picco, & Tarrosa, 2002). These finding speak to the importance of identifying and understanding the hospitalized patient's perception of TF therapy and his/her care needs for the purposes of providing comfort, appropriate and timely communication and information, as well as support for physical and psychological distress during acute illness (Scolapio et al., 2002).

Understanding the patient's perception of his or her care experience is a key factor in health care quality and safety, a factor which can be influenced through patient-centered practices (Institute For Patient and Family Centered Care [IFPFCC], 2011). Patient (or client)-centered care is about providing care that is respectful of, and responsive to, individual patient and family member preferences, values, and physical, emotional, and psychosocial needs, while ensuring that patient and family member values guide all clinical decisions (Institute of Medicine [IOM], 2001). Patient-centered care is a guiding practice principle for a number of health care professions.

Dietitians are closely involved with the management of TF in hospitals, having a primary interest in the patient's physical state of health, the caloric and nutrient content of the food being delivered, and the adequacy of intake (Winkler, 2007). While adept at addressing many of the physical discomforts associated with TF, Dietitians are less attuned to addressing the emotional and social discomforts patients may experience during illness (Gingras, 2010; MacLellan, Morley, Traviss, & Cividin, 2011; Winkler, 2007). As a result, the opportunity to improve patient outcomes beyond the physical, and thereby to positively influence the overall care experience may be lost. Indeed, although patient-centered care is a guiding principle of Dietetic practice (Dietitians of Canada & College of Dietitians of Ontario [DC & CDO], 1997), Canadian Dietitians have indicated that they are unclear about how to translate this concept into practice (MacLellan & Berenbaum, 2003, 2006, 2007).

Studies with patients receiving care from a Dietitian have indicated that patients prefer a more therapeutic relationship, a need for good communication and rapport, sufficient teaching and ongoing emotional support, and an individualized care plan to address highly variable psychosocial and medical issues (Brotherton & Abbott, 2009; Hancock, Bonner, Hollingdale, & Madden, 2012; MacLellan et al., 2011). There is evidence suggesting that Dietitians caring for patients on TF in the outpatient or homecare environment, can provide patients with beneficial teaching and tools to troubleshoot TF as well as provide ongoing support through a multidisciplinary team (Mayre-Chilton et al., 2011; Osborne et al., 2012), with the extent and efficacy of these services requiring evaluation. Indeed, some patients on home TF have attributed receiving a lack of teaching and preparation prior to going home, and poor communication skills and undesirable attitudes among their health care providers as contributing to a negative experience with TF (Brotherton & Abbott, 2009; Brotherton et al., 2006; Jordan et al., 2006). Clearly there is a need for Dietitians and other health care providers to reconsider and enhance their patient-centered practices for patients on TF.

To date only a few, dated studies, using quantitative, approaches have investigated the acute care patient’s experience with in hospital TF (Bruning et al., 1988; Padilla et al., 1979; Padilla & Grant, 1985). These researchers stopped short of illuminating patients’ feelings and insight about negative or positive experiences with TF, such as how ‘distresses’ affected them and why, or the psychosocial implications of being unable to eat. Researchers examining Swedish, recovering, intensive care unit (ICU) patients receiving TF, revealed that as patients regained control over their nutritional situation, their satisfaction with the TF experience improved (Persenius, Hall-Lord, & Wilde-Larsson, 2009). Additionally, the same ICU patients revealed that they were appreciative of the health benefits provided by TF and the support of the professional staff and family members during recovery (Persenius et al., 2009).

Despite these potential benefits to clinical outcomes revealed by Persenius et al. (2009) and an appreciation among some recovering ICU patients of the alleviation of stress related to inadequate nutrition during critical illness, TF remains a therapy little understood for non-critically ill acute care patients other than their known physical and psychosensory discomforts (Bruning et al., 1988; Padilla et al., 1979). How the patient perceives the therapy and these discomforts and experiences the emotional and social impact of being unable to eat during illness, remains unknown for the acute care unit adult population. Additionally, this population's need for information and support to improve their TF experience is not currently illuminated by the extant literature. Understanding the non-ICU, acute care patient's experience with TF and his or her information and support needs, would be a beneficial starting point for Dietitians to improve their practice by identifying different approaches to counseling, teaching, and managing care in a more patient-centered way (MacLellan et al., 2011; Mayre-Chilton et al., 2011).

Purpose of the Study and Research Question

The purpose of this study is to gain a deeper understanding of the adult, acute care patient's experience with impermanent TF in acute care. Specifically, the purpose is to understand the patient's experiences with TF in acute care, the factors contributing to those experiences, and his or her need for information and support from Dietitians and other health care providers. The central question guiding this study is as follows: How do adult, acute care unit patients receiving TF describe their experiences?

Significance of the Study

Optimal care should not just focus on clinical outcomes (Mayre-Chilton et al., 2011). Optimal care must consider and respect the patient's physical, psychological, and social needs including therapeutic interventions and the ongoing management of nutritional therapies (IFPFCC, 2011). Such patient-centered practices may be enabled through an understanding of, and sensitivity to, the patient's whole experience with TF. Addressing the gap in knowledge about the acute care adult patient's experience of receiving TF can provide Dietitians and other health care providers with additional knowledge to adapt their practices and improve the overall experience for this patient population.

Background of Study Focus

Definitions and descriptions of key terms and concepts are provided (in alphabetical order) to clearly delineate what is meant when these terms and concepts are used in this thesis. Additionally, contextual information about tube feeding is provided to both inform and highlight the complexity of this nutritional therapy.

Definitions and Descriptions of Key Terms and Concepts

Acute care patients: are adult patients (>17 years of age) who are acutely ill and admitted to an adult acute care hospital unit other than to a critical care unit.

Clinical outcomes: are defined as the patient's emotional and physical parameters that are affected by the tube feeding therapy and may include: mental state, body weight, hydration, nutrient stores (e.g. vitamins, minerals and protein), and other conditions and situations that would be considered responsive to, or impacted by, adequate nutritional intake such as the patient's disease state, wounds, and hospital length of stay (Brantley & Mills, 2012).

Dietitians: are the experts in the science and delivery of foods and nutrition (College of Dietitians of Ontario, 2012). Dietitians become registered with a provincial regulatory college after completing a minimum-length four-year undergraduate degree in Foods and Nutrition from an accredited university, and a post-graduate internship program (Dietitians of Canada [DC], 2013). The title "Registered Dietitian" is protected, to assure the public of the Dietitian's qualifications and competence (Dietitians of Canada [DC], 2013). The term 'Dietitian' or 'Dietitians' will be used throughout this thesis to denote Registered Dietitian(s).

Over 45% of Canadian Dietitians work in clinical practice providing direct patient (or client) care (Dietitians of Canada [DC], 2011). Dietitians are the health care provider who in different clinical settings, completes patients' nutritional assessment that includes the anthropometrics, biochemical indices, medications, current and past medical conditions, as well as social factors. By collaborating with the patient, family members, and other health care providers, the Dietitian establishes nutritional goals, and in terms of TF, suggests an appropriate regime, and monitors the patient's physiologic, metabolic, and biochemical response to TF, adjusting the regime as needed (Dietitians of Canada [DC], 1996).

Healthcare providers: For the purposes of this thesis, when the term 'healthcare providers' (HCP) is used it is referring to Registered Nurses, Licensed Practical Nurses, and Physicians. Each of these health care providers plays an important role in providing TF as a therapy.

Patient: For the purposes of this thesis, when the term ‘patient’ is used it always refers to an adult (>17 years).

Patient (or client)-centered care: An important aim of patient-centered care is to acknowledge and value each patient’s own way of perceiving and experiencing what is happening to them (Pelzang, 2010). As defined by Dietitians of Canada and the College of Dietitians of Ontario (1997) the client (patient) is the central focus of the professional services that Dietitians provide:

> *The client collaborates and is a partner in the decision-making process [sic] in which to achieve nutritional goals and objectives. This means that the client’s own experiences and knowledge are central, and carry authority within the client-professional partnership. This assumption forms the basis of a client-centered approach wherein mutual respect, trust, and shared objectives are fundamental (p. 4).*

Patient-centered care incorporates the patient’s family members comprised of individuals defined by the patient and family as biological, legal, or emotional relations (Ahmann, Abraham, & Johnson, 2003). Although not specifically stated, for the purposes of this thesis the patient’s preferences, needs, and values are defined and considered within the context of his or her family members, who are collaborative partners in the provision of patient centered-care.

Patient satisfaction: refers to the congruency between a patient’s expectations of ideal care and his/her perception of the real care he/she receives, even though this perception may disregard the appropriateness of therapy and outcomes in their health status (Megivern, Halm, & Jones, 1992). Patient satisfaction is a common outcome measure in organizational quality assurance programs (Vivanti, Ash, & Hulcombe, 2007).

Quality of Life (QAL): refers to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions (Testa & Simonson, 1996). In research there is a continuum of QAL that can be measured. A QAL assessment measures changes in physical, functional, mental, and social health in order to evaluate the human and financial costs and benefits of programs and interventions (Testa & Simonson, 1996).

To effectively measure the impact of a therapy on a patient's QAL and to distinguish between changes in QAL that arise from the therapy and the patient's disease state, assessment tools should be developed and validated for use with the specific patient population receiving that therapy (Testa & Simonson, 1996). To date, only one QAL assessment tool has been created and validated for use with patients with TF (enteral feeding) and this was for the head and neck cancer patient population group; the Quality of Life – Enteral Feeding questionnaire (QOL-EF) (Stevens et al., 2011).

Descriptive and Contextual Information About Tube Feeding

Tube feeding (TF): is a method of providing nutrients through a tube into the gastrointestinal (GI) tract (Stevens et al., 2011). For short term TF (i.e. generally < 1 month), the GI tract can be accessed by inserting a nasogastric (NG) or nasojejunal (NJ) tube through the nose that ends in the stomach or small bowel (Teitelbaum et al., 2005). Longer term TF (i.e. usually > 1 month) is possible through the use of smaller feeding tubes surgically placed in the stomach or small bowel and accessed outside the abdominal wall (gastrostomy and jejunostomy tubes) (Ukleja et al., 2010). The percutaneous endoscopic gastrostomy tube (PEG) is the most common feeding tube used for longer-term access (Fang, Bankhead, & Kinikini, 2012) although the distinction between short-term and long-term is arbitrary. Therefore the specific access chosen is highly dependent on the patient’s clinical, convenience, and tolerance needs, as well as on his/her QAL (Mueller, 2012).

Tube feeding delivery: commonly refers to TF infused via a feeding pump or syringe bolus. The prescribed volume is delivered into the patient’s feeding tube every hour or for intermittent periods, over a twenty-four hour period, depending on the patient’s tolerance, clinical needs, and preferences (Ukleja et al., 2010).

Tube feeding formulae: are commercially prepared, liquid, commonly unpalatable, processed meal replacements designed to meet all individual nutrient requirements (carbohydrates, protein, fat, vitamins, minerals, and electrolytes) in a prescribed volume. There are over two hundred different types of tube feeding formulae available, each with different properties thought to be beneficial for use with different disease states (Brantley & Mills, 2012).

Tube feeding goal: refers to the total volume of TF formula required to meet the patient’s required nutrient needs on a daily basis. The goal volume is calculated using one of several predictive equations available to Dietitians that include variables such as the patient’s weight, height, gender, and/or an estimated level of the patient’s physiologic stress (Cresci, Lefton, & Halasa Esper, 2012).

If the patient’s swallowing function is intact and his or her GI tract is functional, volitional oral intake is appropriate while the patient is receiving TF, regardless of the type of tube delivering the formula. With the understanding that TF is in some cases a temporary therapy, Dietitians endeavor to wean tube feeds while simultaneously encouraging the patient to increase oral dietary intake while maintaining his or her nutrition goals (Wooley & Frankenfield, 2012).

Indications and contraindications for tube feeding. Starvation or prolonged insufficient caloric intake after a 7 to 14-day period is considered unacceptable in Canadian health care settings as it can lead to malnutrition, hence artificial nutrition support therapies, such as TF, are considered standard therapy (Allard et al., 2015; Brantley & Mills, 2012). The decision to provide TF in a clinical setting is dependent on multiple, complex factors including the clinical disorder, GI access, the length of time TF is required, the patient's wishes, and the impact of TF on his/her QAL (Brantley & Mills, 2012; Heyland et al., 1998; Kubrak & Jensen, 2007; Kyle, Pirlich, Schuetz, Lochs, & Pichard, 2004). Indications for TF include patients who have clinical conditions in which oral intake is: not possible, or is inadequate, or unsafe, and who have a functional GI tract (Ukleja et al., 2010). Common conditions necessitating tube feeding in the adult acute care hospital population include: dysphagia secondary to head and neck cancer or neurologic impairments such as stroke, multiple sclerosis, and muscular dystrophy; upper gastrointestinal surgery or gastric stasis; and severe anorexia, and hyperemesis gravidarum (Brantley & Mills, 2012).

Contraindications to TF include the following circumstances: the GI tract cannot be accessed, the disease state or volume of caloric intake does not warrant TF, or the patient and family members do not desire aggressive nutrition support (Amella, Lawrence, & Gresle, 2005). Indeed, the decision to initiate TF for palliative patients or for those who cannot advocate for themselves is often a difficult ethical and legal choice for family members who act as their substitute decision makers (Brantley & Mills, 2012) and underscores the importance of including family members in patient-centered practices.

Tube feeding challenges and solutions. There are multiple barriers to providing TF, a therapy that is not without clinical risk (Heyland et al., 2010; Mitchell, Berkowitz, Lawson, & Lawson, 2000). If provided, TF must be regularly monitored and reassessed, always addressing the concerns of the patient (Mueller, 2012). Tube feeding goals are rarely achieved due to a variety of barriers such as medical TF complications; delays in initiation; frequent interruptions due to tests, procedures, or inadvertent feeding tube removal; and discontinuation because of patient discomfort or post-operative GI concerns (Ukleja et al., 2010). Subsequently, many patients receiving TF are underfed or are started on parenteral nutrition, a form of intravenous nutrition that has an inherent risk for infection and is usually reserved for those patients with inadequate GI function (Whelan, Hill, Preedy, Judd, & Taylor, 2006). Although there is no direct evidence that method of goal determination or that more closely meeting a feeding goal has an impact on clinical outcomes in some patient populations (Braunschweig, Levy, Sheean, & Wang, 2001; Martin et al., 2011), endeavoring to provide the TF regime as intended, based on the Dietitian's assessment, is considered best practice (Heyland, Dhaliwal, Drover, Gramlich, & Dodek, 2003; Mackenzie, Zygun, Whitmore, Doig, & Hameed, 2005).

Healthcare providers, researchers, and health care organizations have developed multiple methods to reduce the risks of TF and to prevent complications (Barrett, Shepherd, & Gibson, 2009; Bowman et al., 2005; Brantley & Mills, 2012; McClave & Mallampalli, 2001). From the medical perspective, practices related to the provision of

TF have improved over the last forty years; however complications, risks, and discomfort related to TF still exist for patients receiving this therapy.

Summary

In this chapter, an overview of the research problem and the significance of studying the stated research question have been presented. Definitions and descriptions of key concepts related to the topic of TF in acute care have been summarized. These terms and concepts, coupled with the contextual information provided reflect the diversity of factors that can influence the patient’s experience. These diverse factors demonstrate the challenge in not only understanding the patient’s perspective but also in establishing sound patient and family centered practices required in the care of the patient population on TF in acute care.

CHAPTER 2

REVIEW OF THE LITERATURE

A literature review was conducted to explore the research literature addressing adult patients' experiences with TF, their need for information and support, and their satisfaction with care. To this end, literature was sought on the patient's perspective of his or her TF experience. In conducting the literature review, studies relating to Nursing and Physician perspectives about TF were found and not included in the review. Rather, these studies informed the researcher's understanding about the care of patients on TF. As a paucity of Canadian studies was found on the patient's experience with TF, U.S., Australian, UK, German, Dutch, Swedish, and French literature was included. Additionally, dated studies were included since overall, the research about TF is limited. The questions guiding this review were as follows:

- What is the experience for patients receiving TF?
- What is their need for information and support, and their satisfaction with care?
- What gaps exist in the current knowledge related to the experience of TF with this population?

Review Methods

A comprehensive search of literature sources was conducted to ensure a broad perspective of tube feeding experiences was explored. The electronic databases of CINAHL, Sage, Academic One File, and Cochrane Reviews were searched for relevant articles published between 1970 and 2013. The "advanced" search method was chosen in all databases and all search terms were prefixed with 'tube feeding' or 'enteral nutrition' and included: patient, dietitian, nursing, physician, perspectives, attitudes, distress, communication, research, satisfaction; and patient (or client)-centered care. Journal articles published in English were chosen if they included subjective experiences of adult patients with the insertion of an enteral access device or with TF in general, that were either qualitatively- or -quantitatively-derived. Additionally, reference lists of the chosen articles were hand searched for relevant titles and this search revealed five additional articles. All articles were critiqued following the Critical Appraisal Skills Program (2013) checklists and a discussion of any study limitations was included in the review.

Results of Review

The final review included articles covering a broad spectrum of TF experiences from predominantly international sources. In total, 16 articles covering the subjective experiences of participants receiving TF, one article about hospitalized patients who experienced NG tube insertion, and two articles about patients' opinions about the possibility of receiving TF, were included in this review. The articles related to tube feeding are summarized in Table 1 (Appendix A) and cover a variety of patient populations consisting of individuals with different TF access devices either hospitalized (acute care and nursing home) or living at home. The decision to include findings based on data collected from those living at home and admitted to nursing homes or ICU was made based on the fact that there was such a paucity of studies to draw from related specifically to the patient experience with TF while in acute care (only 6). The findings of these "other than acute care" studies were deemed informative for the purposes of the study undertaken and reported in this thesis. Additionally articles studying the perceptions about TF from patients and caregivers who did not experience the therapy, were included in this review, as these perceptions revealed interesting information to inform this study.

The Patient's Experience with Tube Feeding

As mentioned, the majority of articles reviewed involved the perspective of caregivers and patients who were living at home, and receiving care either an as outpatient or in their homes. There was limited literature found relating to patients receiving TF in acute care. The chosen articles were descriptive in design and the overall findings relate to the patients' experiences and caregivers perceptions of patients' experiences, with TF. Patients were either hospitalized in acute care or living at home. Results have been summarized into sections. Encompassing these sections are seven themes and sub-themes: impact of TF on QAL (positive impact, depression, and reduced QAL); physical discomfort; lifestyle restrictions; appearance; the meaning of food; changes to routine, identity and social life; and perceived caregiver and healthcare provider support (informational and psychological support). Most articles contributed to several different themes, therefore a brief overview of the study design and results are provided in the initial sections and then only the author(s) is referenced where identified in subsequent sections of the review.

Impact of TF on QAL. Determining the influence of TF on a patient's QAL was a recurrent objective for most researchers of the studies reviewed. The authors of several studies used QAL assessment tools to measure QAL although none were validated specifically for TF patients. Other authors explored factors influencing QAL through open-ended questioning. Findings included both positive and negative impacts to QAL for TF patients.

Generally positive impact on QAL. The perception that TF contributed to survival was a common theme among all those who experienced TF in the studies cited in this review. To determine the impact of feeding via a percutaneous endoscopic gastrostomy tube (PEG) on QAL from the patient's perspective, 51 patients with head and neck cancer recruited from one central Canadian out-patient oncology program who were presently on PEG feedings (n=10) or who had previously had a PEG (1-5 years prior to the study, n = 41) were surveyed using both closed and open-ended questions (Osborne et al., 2012). Although retrospective, results revealed that of the patients no longer receiving treatment, the majority (84%) felt that the PEG feedings had a positive to neutral effect on their QAL and 96% would recommend it to another patient. Twelve of the participants were able to eat food in addition to using the PEG. For those participants who were solely reliant on PEG feedings for nutrition, 73% felt that the PEG feeding was advantageous and another 22% noted that they "wouldn't have survived without it" (Osborne et al., 2012, p. 664). Osborne et al. (2012) also noted that the quality of the PEG tube feeding program at their facility might have contributed to participants' positive experiences as this program included Dietitians who taught patients about the placement, care, and use of the tube and who provided regular follow-up and support to minimize the risk of complications. Not all health care facilities have an outpatient PEG feeding program and if they do, they may not have a similar level of patient support service.

In their qualitative study consisting of semi-structured interviews augmented with a structured symptom rating scale and QAL measure, Osborne et al. (2012) found that for most of the 20 patients interviewed receiving long-term PEG feedings at home in the UK, the PEG dominated their lives with an "appreciable burden of treatment" Jordan et al.

(2006). In addition to these perceptions, 15 of the patient's spoke positively of this route of TF, noting that PEG insertion had been lifesaving. Several patients with relatively high mental health scores displayed resilience in response to their illness and the PEG, noting "acceptance" of the therapy and their illness (p. 270).

Canadian researchers at two tertiary hospitals examined a range of physical, psychological, and social outcomes related to PEG feeding in the seriously ill with shortened life-expectancy (Verhoef & Van Rosendaal, 2001). This follow-up mixed methods study design consisted of data gathered at two points in time using semi-structured interviews and two validated QAL assessments scales, provided by twenty-two seriously ill, hospitalized patients or their caregivers, following PEG placement, and again, in their homes, at one year or after PEG removal (n=10). Although values were not provided, the authors reported that QAL, as measured by a 10-point Karnofsky Performance Scale collected from the patients at the time of 1-year follow-up, improved for most of the patients. The patient's caregivers who completed this QAL assessment tool provided scores perceiving improved QAL for all but two surviving patients, whose scores stayed the same, as well as a better QAL for those patients who's PEG was removed than for those whose PEG was still in place. Only caregivers completed the Quality of Life Index at the end of the study revealing that for patients whose PEG remained in place, most were not managing personal care or light tasks and they were lacking energy, yet they appeared to be more calm and positive than those patients whose PEG had been removed. The majority of the follow-up interviews were conducted with the patients' caregivers given the severity of the patients' illnesses. Results of the baseline interviews were not provided. The negative aspects of TF described by caregivers revolved primarily around the time consuming task of TF, the loss of the pleasure of eating, and the loss of independence. The positive aspects included the ease with which TF could be managed, how it facilitated the care of the patient, as well as providing the patient with improved appearance and better communication with family members. Patients reported general discomforts and complications with TF but also increased physical well-being, convenience, and independence, with all 10 surviving patients stating they would have a PEG again if faced with the same decision, noting that increased length of survival was a key benefit.

In a quantitative study conducted in France, Roberge et al. (2000), examined the impact of home enteral tube feeding on QAL for 30 patients with head, neck, or esophageal cancer receiving NG (n = 24) or gastrostomy (n =6) tube feeds at home, one week, and one-month following insertion. Three validated questionnaires were used to assess QAL including two specific to head, neck, and esophageal cancer, and one designed, but not validated to assess QAL with home enteral tube feeding tolerance. One third of these patients were able to consume some food by mouth. Findings did not differentiate between patients on NG or gastrostomy TF. Results revealed that global assessment scores for QAL and physical function improved slightly between weeks one and four of TF initiation for both nasogastric and gastrostomy-fed patients.

Brotherton et al. (2006) used semi-structured interviews to qualitatively assess the impact of PEG feeding on patients with a range of clinical diagnoses, beyond upper GI disorders, living at home and their caregivers. In terms of closed-ended questions, reported quantitatively, overall the 15 patients interviewed felt their QAL was acceptable and one patient reported feeling “100% better” following PEG insertion. Participants also reported that PEG feedings provided a sense of security for their nutritional health. They were thankful for the relieved pressure to eat at mealtimes given the substantial difficulties encountered with eating a healthy diet prior to the PEG insertion.

Meyer-Chilton, Talwart, and Goff (2011) found that their sample of six patients with head and neck cancer and three caregivers in the UK also reported in a focus group, feeling the benefit of added security and improved health while on gastrostomy feedings at home for three months. The main benefit of TF was weight management given the patient's weight loss prior to initiation of TF. Additionally participants acknowledged that their positive coping strategies were helpful in dealing with the side effects of gastrostomy feedings and that TF contributed to their survival.

Gastrostomy feeding was found to have a positive impact on QAL in 55% of patients with a variety of disease states either hospitalized, living at home, or living in a nursing home in the UK (Bannerman et al., 2000). Bannerman et al. (2000) used two standardized questionnaires to assess QAL among 55 patients who had previously received or who remained on gastrostomy TF as well as among 54 additional patients scheduled to undergo gastrostomy tube insertion. Results did not differentiate between those patients who remained hospitalized, were living at home, or who were living in a nursing home. Additional findings from the QAL scales of the group studied prospectively included deficiencies in the physical domain but not for mental function (anxiety or depression), energy, or health perception.

The value of TF as a therapy in maintaining a positive to neutral QAL was noted in the study by Senft et al. (1993). These authors compared head and neck cancer outpatients undergoing radiotherapy and either eating an oral diet or receiving PEG feedings, using a questionnaire to assess QAL that was not reported as validated. The values used to measure QAL remained constant for the patients on PEG feeding throughout the duration of radiation therapy (18 weeks) as compared to the significantly reduced QAL values for patients dependent on oral intake alone.

Among the elderly living in nursing homes for whom the decision to provide TF may be controversial if they are mentally impaired, comatose, or terminally ill, it is interesting to note that the attitudes of residents not receiving TF were explored. Keyser-Jones (1990) conducted an anthropological study in three nursing facilities in the U.S with 103 residents with at least moderate cognitive function. Fifty-three percent of these residents wanted to be tube fed rather than die should the need arise, given the value they placed on life. The authors noted that although the residents may not have been aware of all the potential consequences of TF, their responses were strengthened by the fact that they observed others being tube fed and had discussed it among themselves.

The author of a phenomenological study explored the psychological effects of PEG feeding on 12 patients living at home and eight caregivers in the UK using interviews (Rickman, 1998). There was no evidence of author reflexivity throughout the article, nor did she disclose using validation strategies. Therefore her interpretation of the data lacks a degree of credibility. The author noted the high degree of ambivalence that existed among patients and caregivers with respect to long-term PEG feeding. Most participants expressed gratitude for the nutritional benefits of a PEG but also stated dislike for the tube. Others regretted their decision to have a PEG given the multitude of discomforts and problems associated with the therapy, with the perception that it impacted their QAL negatively.

In their grounded theory study, Persenius et al. (2009) found that among the 14 critically ill tube fed patients interviewed at various points during their ICU stay, satisfaction with the nutrition experience improved as they were able to 'make sense of their nutritional situation' and became more 'involved with nutritional care'. Making sense of the nutritional situation involved: considering food as necessary in their lives and their recovery process; considering former nutritional experiences as sources of knowledge, recognition, and comparison for improving their comprehension and understanding of the nutritional situation; and that the outcome of their nutritional care was positive if their body weight was stable, nutritional needs were being met, and if the nursing staff were supportive. Being involved in nutritional care included "handing over nutritional care to health care professionals" and included patients being "confident" in the health care professionals and feeling "safe" because the staff ensured the TF was running properly. Additionally, participants were more satisfied when offered the opportunity to make choices, take part in decisions about their care, and involve their next of kin. Finally, ICU participants felt more hopeful when physical discomforts such as thirst, poor appetite, and abdominal discomfort were alleviated.

Generally negative impacts on QAL. Assessing psychological factors such as depression ("feeling down in the dumps") are fundamental measurements in health QAL scales (Testa & Simonson, 1996, p. 837). A number of patients hospitalized or living at home receiving, or who had previously received, PEG, gastrostomy, or NG feedings perceived that their QAL on TF to be adequate (Bannerman et al., 2000; Brotherton et al., 2006; Osborne et al., 2012; Roberge et al., 2000). Whereas other participants felt that TF had a negative impact on their QAL secondary to the multitude of discomforts, sensory deprivation, and social losses experienced (Brotherton et al., 2006; Jordan et al., 2006; Rickman, 1998; Roberge et al., 2000; Verhoef & Van Rosendaal, 2001). Intensive Care Unit patients in the study by Persenius et al. (2009) experienced worry, fear, and failure during nutritional therapies secondary to being thirsty, having changed appetite, 'having eating and swallowing difficulties', and 'having abdominal discomfort'. The authors noted that because ICU patients could not handle these problems themselves, they felt helpless and dependent on the health care professionals.

A qualitative study by Walker (2005) explored the experiences of patients unable to eat and living at home with a feeding tube. She interviewed 16 U.S. patients and their caregivers receiving PEG feedings six months after placement. Feelings about living with PEG feeding were: sad, frustrated, depressed, lonely, difficult, hard, angry, mad, deceived, hell, upsetting, and uncomfortable. Patients and caregivers at home on PEG feedings expressed similar comments in the study by Rickman (1998), as well as the study by Brotherton et al. (2006) with one patient mentioning being prescribed antidepressants. Sixty-nine percent of the 30 patients on NG or gastrostomy feeds in the Roberge et al. (2000) study longed to have the feeding tube removed, and four patients reported depression since starting TF and scored lower on emotional functioning in the QAL survey.

Jordan et al. (2006) found that during interviews, several home PEG fed UK patients showed evidence of depression and anxiety, and mental health scores were below those of both the general population and those with chronic illness. Mental health scores indicated a wide range in responses (8.8-62.7), and the authors concluded that this reflected patients' varying degrees of resilience, adaptation, and disability. Roberge et al.

(2000) suggested that the emotional response to TF depended on the patient's underlying disease, prognosis, and personality characteristics, acknowledging the difficulty in isolating TF as an independent predictor of QAL.

Physical discomfort. Physical discomforts associated with all types of TF were commonly reported in the majority of studies cited in this review. Although dated, Padilla et al. (1979) conducted a landmark study with acute care patients receiving TF. In this quantitative study with 30 U.S. patients receiving TF through a nasogastric tube (NG) the authors investigated the type, incidence, and subjective level of distress associated with TF using the "Tube Feeding and Hospital Experience Checklist (TFHECL)". The authors developed this tool but no validation was reported. Patient experiences were reported as causing distress if experienced by greater than half of the participants. Common distresses included sensory irritations such as soreness, thirst, dry mouth, runny nose, having a tube in the nose, breathing through the mouth, and breathing with a tube in the nose. Although demographics were not reported, the authors noted that a "large number" of their subjects had cancer or surgery of the ear, nose, throat, and neck, or trauma to skin or membrane of the face and throat. As these subjects also reported soreness, the authors noted it was difficult to determine whether some of the distress was a consequence of the injury, rather than the NG tube. Gastrointestinal symptoms were not common, but those reported included: abdominal cramps, regurgitation, having a "bad taste in the mouth", heartburn, bloating, constipation, hunger, gas, diarrhea, nausea, and vomiting.

Similar physical distresses were expressed by ICU patients (Persenius, 2009). Being thirsty was described as bothersome, "I am so thirsty I can drink a whole bucket of water at once. I feel such craving…I'm just longing for something to drink." Patients expressed fear and failure with swallowing difficulties as well as frustration with altered bowel habits causing abdominal discomfort. Lastly, mouth dryness and the feeding tube, which was experienced as unpleasant and repulsive, were described as physical discomforts.

The common GI problems among hospitalized patients on NG TF were also noted as problematic for patients on NG, PEG, and gastrostomy TF living at home, whether early in their TF treatment or after several months (Brotherton et al., 2006; Jordan et al., 2006; Osborne et al., 2012; Roberge et al., 2000; Verhoef & Van Rosendaal, 2001).

In another dated, quantitative study of 20 hospitalized, post-operative, head and neck cancers patients with NG TF, Bruning et al. (1988) found similar GI distresses and complications related to the feeding tube, using a structured “malaise” checklist questionnaire and the same “Tube Feeding Hospital Experience Checklist” developed by Padilla et al. (1979), neither tool reported as having been validated. Over 50% of participants complained of thirst, dry mouth, and having to swallow more than usual, as well as having a sore nose or throat and a running nose.

Morrison et al. (1998) conducted a quantitative study with 100, alert hospitalized U.S. patients who were asked to rank the pain and discomfort associated with sixteen common hospital procedures. Nasogastric feeding tube insertion was considered moderately painful and was ranked the most uncomfortable. Indeed, feeding tube insertion, as well as the ongoing presence of the tube has been found to contribute to a patient’s general discomfort. Sleeping difficulties were noted by patients in several of the studies cited regardless of the feeding route, length of time on TF, and whether hospitalized or living at home (Brotherton et al., 2006; Bruning et al., 1988; Jordan et al., 2006; Osborne et al., 2012; Roberge et al., 2000; Verhoef & Van Rosendaal, 2001). Physical and technical problems commonly reported for those with gastrostomy and PEG tubes included: blocked tubes, bleeding, skin breakdown, malodorous leakage, and infection around the tube insertion site requiring antibiotics (Brotherton et al., 2006; Jordan et al., 2006; Osborne et al., 2012; Verhoef & Van Rosendaal, 2001; Walker, 2005).

Highlighting the need to understand and respect the patient's perception of discomfort, Majid, Emery, and Whelan (2012) administered a cross-sectional survey in the UK, using a structured questionnaire to understand the individual definitions of diarrhea experienced during TF among three groups: 22 patients receiving TF, 57 Nurses, and 33 Dietitians; their attitudes toward diarrhea; and the management practices of Nurses and Dietitians, related to diarrhea. The definition and perceived discomfort of diarrhea among these patients receiving TF differed from what was reported by the Nurses and Dietitians. To improve patient-centered care,Majid et al. (2012) suggested that health care professionals inquire about patients' symptoms and how diarrhea is affecting them when reported, rather than assume the definition and discomfort is understood.

Patient perceptions of comfort among those with limited or no experience with TF has also been studied, and results highlighted the stigma associated with this therapy in certain population groups. Among the 103 nursing home residents interviewed about their perceptions of TF in the Keyser-Jones (1990) study, 40% did not want TF if faced with the choice, secondary to a fear that the tube would choke them, obstruct their breathing, be painful, or interfere with organ function. Keyser-Jones (1990) noted the importance of communicating appropriate and timely information about TF to residents and families, and encouraging residents and families to express their wishes about artificial nutrition and for staff to note this in their medical records.

In a more recent U.S. study examining the artificial nutrition support preferences (TF versus parenteral nutrition) of 101 hospitalized oncology patients who were not receiving artificial nutrition support, 91% indicated they would prefer parenteral nutrition regardless of the Physician's recommendation and whether or not they had received TF in the past (Scolapio et al., 2002). Using a self-administered questionnaire, the researchers found patient perceptions of the comfort of any given feeding method to be the most important determinant of preference. The authors suggested that where possible, patients be given a choice as to the feeding method adopted, as considering their wishes during illness and offering choices may well enhance comfort, rest, and healing during hospitalization.

Lifestyle restrictions. The presence of a feeding tube, the associated equipment, and the physical discomforts associated with TF may restrict a patient's daily activities. Hospitalized patients in the Padilla et al. (1979) study who were receiving NG feedings reported tube-related mobility limitations as distressing. Patients in the UK on PEG feedings reported feeling restricted in clothing choices as well as being uncomfortable leaving the house or going on vacation, given the time required to infuse the feeding formula, the cumbersome TF paraphernalia, and the potential side effects such as tube leakage or odor (Brotherton et al., 2006; Jordan et al., 2006; Rickman, 1998). Of the 30 participants on NG or gastrostomy TF in the Roberge et al. (2000) study, several reported induced discomfort in daily activities such as dressing (40%) or washing (54%) and many did not resume either their daily activities (25%) or leisure activities (20%) following initiation of TF.

Appearance. The qualitative study by *Walker (2005)* also explored what happened to self-identity in everyday life when people lose the ability to eat. She found that patients viewed the PEG as a visible and alien fixture to the human body, which could be seen as a physical deformity and a nuisance. A patient on PEG feedings reflected this in his comment about the tube: “The way the tube is designed is one of the worst things about it. It always gets in my way. My wife and I have learned how to tie it tight against me with a long shoestring. But even then, you see it under my shirt” (p. 172).

The effect of feeding tubes on cosmetic appearance was considered important by a number of patients and their caregivers based on results of several studies cited in this review, regardless of the type of tube. Fifty-three percent of the 30 patients on NG or gastrostomy feedings found to be intolerant of TF in the Roberge et al. (2000) study, felt uncomfortable about their body image and sexuality, regardless of whether TF was provided via a NGT or gastrostomy tube. The authors did not correlate this finding with other participant characteristics such as body weight or disease state. Greater than 50% of the 30 patients in the Padilla et al. (1979) study found that “having others see me with a tube in my nose” to be distressing. The smaller gastrostomy or PEG tubes were also found to contribute to discomfort with appearance among patients on home TF in the studies by Bannerman et al. (2000) and Osborne et al. (2012). However, the patient caregivers in the study by Verhoef and Van Rosendaal (2001) noted improved physical appearance when the patient was switched from an NG to a PEG tube.

The meaning of food. Receiving nutrition through a feeding tube may provide adequate nutrients to sustain life, but the implications of being unable to eat and enjoy food and beverages may have consequences on a patient's QAL. Using interviews and a semi-structured questionnaire to address the social and symbolic meaning of food with 16 patients on PEG feedings living at home Walker (2005) found they mourned the loss of eating what they referred to as "real" food. Patients made comments such as "I wanted to eat, I mean chew and swallow real food. I knew with my mind that I was getting some nutrition through my tube but have you seen that stuff? It's just liquid mush, not real food" (p. 172). Similar findings were noted from other qualitative studies with patients who were living at home on PEG or gastrostomy feedings (Brotherton et al., 2006; Meyer-Chilton et al., 2011; Rickman, 1998; Verhoef & Van Rosendaal, 2001). The patients and their caregivers involved in these studies perceived loss of the pleasure of eating and the continuing desire to eat as a negative consequence of PEG feeding, with one participant from the Brotherton et al. (2006) study noting that quality of life although acceptable, was now "boring" without food (p. 361).

Hospitalized patients also mourned the loss of eating during their acute illnesses. Described as sensory discomforts, the findings in the study by Padilla et al. (1979) included unsatisfied appetite and the deprivation of tasting, chewing, swallowing, and drinking among greater than 50% of the respondents. These patients also noted disruption to normal stimuli such as "not knowing when I've had enough food" and "having a poor appetite" as distressing. Bruning et al. (1988) found similar results in greater than 50% of the 20 hospitalized patients receiving NG feeding. Reported distresses of "feeling deprived of tasting food and drinking liquids" as well as "having an unsatisfied appetite for certain foods" remained after 21 days of TF, while the other distressful experiences diminished.

The ICU patients in the study by Persenius et al. (2009) reported similar sensory deprivations, from no appetite at all to being so hungry that the food could not be served fast enough. The smell, taste, and temperature of the tube feeding formula as well as the food and fluid ingested had a negative impact on appetite with patients noting that it was "strange" to have no appetite or desire for food (Persenius et al., 2009). This group of hospitalized patients also felt that food, even in tube feeding form, was necessary in their lives and as well as for their recovery process. The authors noted that it was important for patients to consider the meaning of nutrition to find out if they possess the motivation and desire to cope with nutritional changes.

In their quantitative, longitudinal study on QAL following gastrostomy, Bannerman et al. (2000) noted that at one and six months following tube placement, several patients living at home expressed concerns about whether they were receiving adequate nutrition and were worried about their weight. The authors suggested increased patient monitoring and the importance of establishing clear nutrition goals with patients from the outset of TF.

The image of TF as being a medical intervention and the importance of food being a personal choice is evident among the nursing home residents who were noted, in the study by Keyser-Jones (1990), to object to TF because they viewed it as punishment for not eating, or a therapy reserved for the mentally impaired. Other residents were unhappy with life in the nursing home and so would refuse TF in protest. Keyser-Jones (1990) underlined the importance of addressing resident concerns with conditions in the nursing home prior to accepting residents' refusal of food or hydration, and suggested regular evaluation of dietary intake.

Routine, identity, and social life. Tube feeding of any type can disrupt patients' daily routines as well as impact their enjoyment of social events or situations, especially when food is involved. Walker (2005) found that preparing meals for others was often a part of an individual's social identity, such as being the cook for the household, while for others, preparing and eating meals defined their daily routine. One patient with a PEG found it difficult to keep track of the time because she was no longer preparing meals, stating that: "Now the days just seem like one big thing" (Walker, 2005, p. 171). Walker (2005) concluded that the designated times and patterns of eating not only help divide the day but connect individuals to the social structure in which they live.

Researchers of several of the qualitative and quantitative studies included previously in this review, highlighted feelings of sadness and isolation among study participants living at home with a PEG, gastrostomy, or NG tube when referring to their inability to prepare meals, eat with others, and maintain a daily mealtime routine (Bannerman et al., 2000; Brotherton et al., 2006; Jordan et al., 2006; Rickman, 1998; Roberge et al., 2000). Bruning et al. (1988) found greater than 50% of their hospitalized patients on NG feeding found "feeling deprived of socializing while eating" as distressing (p. 186). So clearly, this is a problem not exclusive to patient's living at home. Walker (2005) surmised, that "loss of the ability to eat was experienced as a social bereavement" (p. 167). When unable to eat and participate in meals and special occasions, many UK and French patients receiving TF at home by PEG, gastrostomy, or NG withdrew from social situations as a coping mechanism (Brotherton et al., 2006; Jordan et al., 2006;

Rickman, 1998; Roberge et al., 2000). On the other hand, Walker (2005) found some patients sought consistency by choosing to have family members continue preparing them meals (despite not being able to eat) and sitting with others during meals to maintain a social connection.

Social isolation experienced by tube fed patients was compounded by the feelings and actions of family members or caregivers as well as by the patient's feelings and perceptions. Jordan et al. (2006) and Walker (2005) found that caregivers of home PEG fed patients were uncomfortable eating in front of the patient and would often eat in another room or eat cold foods so that the patient could not smell what they were eating. Other participants on PEG feeds at home reported TF as having a persistent negative impact on current intimate relationships and on opportunities to develop new ones (Brotherton et al., 2006; Meyer-Chilton et al., 2011; Osborne et al., 2012; Rickman, 1998). Roberge et al. (2000) found that 16 of 30 NG or gastrostomy fed patients were intolerant of TF and had significantly higher 'poor body image/sexuality scores ($P = 0.004$) and higher 'poor social functioning scores ($P = 0.055$) in their QAL assessments than did the other patients who were considered to be tolerating TF. These findings were independent of socio-demographics, feeding route, tolerance to TF, and predisposing diagnosis. Walker (2005) concluded that patients on PEG feedings faced establishing a new identity that could be stigmatized or spoiled.

Perceived caregiver and healthcare provider support. The experience of patients on TF may be influenced as well, by patient perceptions of the degree of support provided by caregivers or family members, and the healthcare professionals who manage their care. This support can take the form of assistance with equipment and administering

TF, regular and consistent multidisciplinary team or individual provider involvement, consistent information provision, collaborative decision-making, and teaching activities, as examples.

The majority of TF studies reviewed suggested that both hospitalized patients and those living at home had caregivers who were highly involved in their care, although the degree to which caregiver support influenced the patient's QAL was not clearly reported (Brotherton et al., 2006; Jordan et al., 2006; Meyer-Chilton et al., 2011; Osborne et al., 2012; Rickman, 1998; Roberge et al., 2000; Verhoef & Van Rosendaal, 2001; Walker, 2005). An exception is the study by Persenius et al. (2009)who noted that the ICU patients in their study were very pleased when caregivers brought in to the hospital, favourite foods and fluids and assisted them with eating, contributing to increased satisfaction. Additionally, these ICU patient participants reported positive outcomes with tube feeding as safe, supportive, nutritional care as well as the importance of attention, encouragement, and information from health care providers. Theses authors noted that supportive care settings promoted feelings of safety and reduced the patient's perception of being vulnerable.

In the study by Rickman (1998), having regular access to a supportive health care professional such as a Dietitian was noted as helpful by one patient living at home with a PEG who found the Dietitian "marvelous" (p.727), as she was always available via telephone to help. Another patient from the same study felt the Nurses should have been better informed as they were the health care professional with whom he or she had closest contact. Rickman (1998) concluded that participants would have benefited from regular access to a multidisciplinary supportive clinic such as the one described in the study by

Persenius et al. (2009). Expressed as a positive factor among UK patients living at home with gastrostomy tubes, participants in the study by Mayre-Chilton et al. (2011) had access to a hospital-based specialist team, which included a registrar, dietitian, nurse, and other professionals in their oncology clinic. This support network is similar to the one described as available to the Canadian outpatients with PEGs in the Osborne et al. (2012) study, although the question of impact on patient satisfaction was not posed to those participants.

Greater than 70% of PEG fed patients and their caregivers living at home in the Brotherton et al. (2006) study, felt sufficiently supported by healthcare professionals; the third who did not, noted confusion with conflicting messages from different healthcare providers. The caregivers interviewed in the study by Jordan et al. (2006) noted that they did not receive adequate training about PEG feeding before patient discharge, and that they needed more support when they initially returned home. These participants also noted frustration with the lack of knowledge about TF among non-specialist healthcare providers such as district nurses, general practitioners, hospital doctors and nurses, as well as health care providers in emergency departments.

As an outcome of their study, Brotherton et al. (2006) created an adult "Impact of Living with a PEG" questionnaire that they suggested be completed by patients and caregivers prior to consultation with the healthcare provider at the time of PEG insertion, to highlight issues the patient and caregiver may face during feeding and to facilitate planning appropriate support. For patients and caregivers struggling with the decision of whether to choose TF at the end of life, Verhoef and Van Rosendaal (2001) suggested time-limited trials be offered, providing patients and families with time to evaluate outcomes and to adjust to the inevitability of death.

Informational support. Rickman (1998) found many patients living at home with a PEG and their caregivers in the UK felt they were not well informed about the goals of PEG feeding and what to expect. A follow up qualitative study by Brotherton and Abbott (2009) was conducted with 27 care givers and 16 UK patients at home on PEG feedings, to explore their perceptions about the adequacy of the information provided and their subsequent involvement in the decision-making process for PEG insertion. Results revealed that only four patients and 10 caregivers felt that they had received enough appropriate information regarding the PEG, such as anticipated time spent feeding, how feeds would be provided, and where and how to access the equipment. Patients identified barriers such as poor communication and a paternalistic and prescriptive attitude among the health care professionals. The authors suggested that health care professionals should develop interdisciplinary and participative practices facilitating agreement on shared treatment goals and evaluation of patient experiences.

Roberge et al. (2000) noted that both oral and written teaching about NG and gastrostomy TF was provided by the Dietitian prior to hospital discharge, including a description of the technique, specific recommendations, and advice regarding problems that can occur while on TF. The impact of the Dietitian's interventions on the patient's experience was not directly examined in the study. Additional practical suggestions to improve the reporting and management of TF distresses included administration of a symptom checklist to patients, with management guidelines for treatable conditions while ensuring evaluation to avoid over-reporting of adverse effects in healthy patients (Jordan et al., 2006).

Psychological support. Padilla et al. (1979) provided practical suggestions to ameliorate psychosensory distress with TF such as permitting the patient to chew and spit out favourite foods, and administering TF during regular meal times with others. Six years later, Padilla and Grant (1985) published a follow up, randomized, experimental, pre-and post-test study whereby 35 hospitalized patients who had been on NG feedings for 24 hours were randomly assigned to receive one of four different eight-minute education films. The authors provided limited information as to the content, but listed the educational films as covering one of the following topics: the TF procedure; coping behaviours for the TF procedure; the sensory experiences commonly associated with TF; and combined information on coping behaviours with specific sensory experiences. The patients rated their levels of anxiety and discomfort with TF prior to the film and at two other points within a second 48-hour period, which included a second showing of the same film. The authors found anxiety and discomfort decreased the most in the groups viewing the films on sensory experiences and TF procedure. The participants who viewed the sensory experiences film were more likely to feel that they had perceived control over the TF and were more willing to repeat the TF experience than those participants who viewed the other films. Padilla and Grant (1985) concluded that tube fed patients' anxieties should be dealt with by the primary treatment team, i.e. the patient's Physician, Nurse, and Dietitian, and that some patients should have a psychiatric consultation. Finally, the authors recommended studies testing the effectiveness of specific care interventions in preventing or reducing psychosocial problems and in improving quality of life of patients on nutrition support.

Researchers have acknowledged the need to understand the patient's perspective to improve the effectiveness of, and satisfaction with, Dietetic care (Hancock et al., 2012). To assist patients with developing positive coping strategies, numerous authors of the studies cited in this review suggested that health care professionals including Dietitians, provide a supportive counseling framework covering psychological, emotional, and social support in conjunction with a knowledgeable multidisciplinary team (Brotherton & Abbott, 2009; Brotherton et al., 2006; Jordan et al., 2006; Mayre-Chilton et al., 2011; Roberge et al., 2000). Taken together, this support by health care professionals would involve what is now commonly-termed patient-centred care.

Conclusion

The purpose of this review was to explore the research literature to understand adult patients' experiences with TF, their need for information and support, and their satisfaction with care. In addressing this purpose, this review has illuminated the wide range of positive and negative impacts and physical and psychosocial distresses experienced by patients receiving gastrostomy or PEG TF while living at home, as well as their need for teaching and support. Multidisciplinary patient-centered practices have been suggested to support this patient population and these require evaluation for their impact on the patient’s experience and satisfaction with TF. Less understood is the experience of the acute care adult patient receiving TF, and his or her particular care needs. Thus a gap exists in the knowledge base of Dietitians and other health care providers seeking to provide patient-centered care to improve patient satisfaction with TF therapy during acute illness.

CHAPTER 3

METHODS

In this chapter the theoretical scaffolding underpinning the study approach, the ethical considerations, and the strategies implemented to ensure rigor are described. The steps taken with respect to data collection and management, and analytic activities including unitizing, categorizing, and constant comparison, are made explicit. For much of this chapter, the first person will be used for the sake of readability, as appropriate.

Study Approach

The interpretive description (ID) qualitative research approach developed by Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) was chosen to answer the research question: how do adult patients undergoing tube feeding in acute care describe their experience? Interpretive Description was chosen to direct the study because: a) it provided a logical philosophical framework to investigate the clinical phenomena of TF in acute care; b) it facilitated a contextual understanding of the patient's experience with TF in acute care, allowing for an interpretation that provides dietitians with a new angle of vision; and c) it facilitated the translation of the interpretive description into practical clinical knowledge and future research objectives for dietitians that can be used to make a difference in the care of acutely ill patients receiving TF in acute care.

According to Thorne (2008), ID serves as a framework for the researcher to choose data collection and analytic strategies that meet the criteria for methodological coherence, in order to create or uncover credible, and defensible new knowledge in a form that will be meaningful and relevant to the applied practice context. Studies generated with ID are grounded in the philosophy informing this methodology as well as the position of the researcher. The researcher should be comfortable with who he/she is, what he/she represents, and be clear on what he/she is trying to accomplish (Thorne, 2008). The philosophical foundation of an ID will be discussed and my intellectual position will be made explicit.

Philosophical Underpinnings

All inquiries are bound by a set of assumptions about human experience and about the nature and production of knowledge pertaining to it (Thorne, 2008). Interpretive description has a philosophical foundation in interpretive naturalistic inquiry by Lincoln and Guba (1985), which is built upon several basic assumptions: a) there are multiple constructed realities that can be studied only holistically. Thus reality is complex, contextual, constructed, and ultimately subjective; b) the inquirer and the "object" of inquiry interact to influence one another; indeed, the knower and known are inseparable; c) it is impossible to distinguish between cause and effect, and d) inquiry is value-bound (Lincoln & Guba, 1985; Thorne et al., 2004, p. 5). Researchers subscribing to these assumptions enter an ID assuming that a priori theories cannot encompass these multiple realities; rather, theory emerges from the phenomenon (Thorne, 2008). Collectively, these assumptions represent the epistemological foundation of an ID inquiry and inform the research design.

Building a credible ID study involves establishing an initial position from which design decisions and analytic exercises will be made so that conclusions flow logically from the original objectives, and the results are meaningful (Thorne, 2008). Thorne (2008) describes establishing this initial position as "scaffolding" (p. 53), which involves two critical elements: 1) the review of the literature, and 2) positioning the researcher, which includes making explicit any: theoretical allegiances, disciplinary heritages, and personal links to the phenomena of interest. The literature review provided comprehensive knowledge about TF, thus confirming that the stated research question requires answering and is significant. Additionally, the literature review illuminated who has already studied the question, their approaches, and the conclusions they have drawn, contributing significantly to the design of the present study. To further explain the scaffolding informing the proposed study design, thorough explanations of the factors, which position myself in the study, are provided.

Theoretical allegiances

Interpretive description studies, being located outside the social science theoretical tradition, do not require positioning within formal theoretical frameworks (Thorne, 2008). Indeed, this proposed study is informed by two practice theories and one formal theory, central to sociology. These theories, although not a part of the proposed study design, require mentioning for their influence in sensitizing the researcher to certain elements that are applied within the context of this study (Sandelowski, 2000): the actions of practitioners caring for patients in the hospital setting; the impact of food and TF on self, and in relation to others when unable to eat; and the experiences of patients receiving TF in the ICU.

With patient-centered care being a core concept within the larger conceptual framework of this proposed study, theories relating the patient-centered processes employed by health care providers were considered. Vandall-Walker, Jensen, and Oberle (2007) revealed the grounded theory of nursing support from the perspective of Canadian family members of critically ill adults. In this study, family members felt supported when nurses were “Lightening Our Load”, the core category of this process, which included nurses enacting specific behaviours to support (by enabling) family members' getting through the critical care experience with the least amount of suffering possible (Vandall-Walker et al., 2007). Providing support through collaborative mechanisms based on developing a relationship with patient’s and families is a core concept of patient-centered care and has been further clarified as a nursing support process, thus informing the practices of nurses and indeed, other health care providers.

In understanding how being unable to eat affects people on home TF, Walker (2005) applied the symbolic interactionist perspective from sociology, to illuminate the implications of food meaning and how such meanings are intrinsically connected to issues of identify. Not only does this study, being framed by the symbolic interactionist theory, demonstrate that the loss of the ability to eat has a significant effect on social interactions and identity, it also reinforces the conflicting meaning that TF has for participants, that artificial nutrition and hydration cannot be considered food, but rather are seen as a medical treatment (Walker, 2005).

For patients receiving TF and other forms of nutrition during their illness experience in acute care, the process of “grasping nutrition during the recovery process” in the ICU (Persenius et al., 2009, p. 166) has been considered. This study highlights the improvements in patient satisfaction that can be realized as ICU patients grasp nutrition as a way to regain some control in a situation where they are highly dependent on professional care. Despite differences in the trajectory of patients’ illnesses and the structure and practice of the different professional care teams, in the current study of adult acute care patients receiving TF, similar findings such as those seen in the ICU population may be illuminated. However the proposed study findings are not intended to confirm or disconfirm the theories of “grasping nutrition during the recovery process”, the process of nursing support, or social interactionism. All theories presented were kept aside and considered as part of the reflexive process when conclusions were drawn about the study findings.

Thorne (2008) indicates that in an ID study, researchers may borrow analytic methods from traditional qualitative approaches as long as justification for what has been borrowed is provided along with explicit adherence to the assumptions and linguistics of each research culture. In the proposed study, analytic methods and techniques used will be a blend, borrowed from naturalistic inquiry (Lincoln & Guba, 1985), and the research traditions of psychology (phenomenology), and sociology (grounded theory) (Thorne et al., 2004). An explanation of the application of these analytic methods and techniques will be provided in the “Data Analysis” section of this thesis.

Disciplinary heritages

This study was framed by and for the discipline of Dietetics. The distinguishing angle of vision for Dietetics is in the profession’s scope of practice, which is to bridge the gap between the scientific knowledge of foods and nutrition with the complex, multiple functions that food has in people’s lives in order to attain, maintain, or promote their health (DC & CDO1997; Swift & Tischler, 2010). For Dietitians working in the hospital setting, practice is inhibited by an imbalance in the source and type of knowledge favoured about TF, where research stemming from a realist ontological position is valued over the knowledge derived from multiple constructed social realities (Gingras, 2010; Winkler, 2007). Being generally uninformed about the 'individual' experience with TF, Canadian Dietitians remain unclear about how to employ patient-centered practices, including addressing patient’s emotional concerns, possibly contributing to the difficulties Dietitians experience in attaining practice goals (MacLellan & Berenbaum, 2003, 2006, 2007; MacLellan et al., 2011). Hence, this study constructs an ID of the patient’s experiences with TF in acute care to inform Dietitians’ deeper appreciation of what their appropriate clinical response should be in any given situation. This study aims to create an empirical basis from which new practice questions can be generated, and answered, building the foundation for a substantive body of knowledge about TF for the profession of Dietetics (Thorne, 2008).

Positioning personal links

Qualitative research capitalizes on the researcher being the “instrument” of the research (Thorne, 2008, p. 69). As the credibility and quality of the research are dependent on the intellectual integrity of the researcher, I will disclose my ideas, thoughts, perspectives, or personal experiences that may influence the angle of vision informing the study, while managing and accounting for them (Thorne, 2008).

I have several years of both personal and professional experience with TF, beginning as the teen-aged sister of an older sibling who required NG TF in the hospital and eventually at home. That personal experience shaped my perception of TF as being both an advantageous and a highly uncomfortable therapy, instilling in me a desire to help people through the benefits of nutrition. With a strong value system grounded in relationships, giving and helping others, and health and balance, I pursued a career in Dietetics. I am knowledgeable about the science of nutrition support therapies, having cared for patients on TF in the hospital, and other settings, for over 12 years while simultaneously being a preceptor to Dietetic interns. However, the emphasis of Dietetic teaching on positivist epistemologies has left me challenged to remain open to the value of constructed realities and hence navigate the complexities of the subjective experiences of patients in practice. Consequently, I left clinical practice due to disillusionment.

The disconnect between patient's negative experiences with TF and the lack of patient-centered practices employed by Dietitians and interns to help patients, remains concerning. The Masters of Health Studies program has exposed me to alternative paradigms and epistemologies, providing an understanding of and appreciation for the value of learning the varied patterns and themes within the subjective experience of the patients/clients cared for as a basis to inform Dietetic practice.

My experiences with TF and the perceptions and biases I held were outlined in a reflexive journal (Thorne, 2008). These perceptions and biases were frequently referred to and discussed with my supervisor to ensure that they remained in the foreground. Thus I remained aware that my experiences, perceptions, and biases were potentially shaping what I observed and heard when interviewing patients and could have influenced the findings, the conclusions, and the interpretations drawn (Creswell, 2013). A discussion of ways that biases and their potential influences were countered is included in the "Ensuring Rigor" portion of this thesis.

Ethical Considerations

As acutely ill, hospitalized, adult patients were recruited and individually interviewed for this study the ethical considerations outlined by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Panel on Research Ethics, 2014) was followed to minimize risks to participants' autonomy, health and welfare, privacy, and confidentiality. Additionally, omitting the institutional names and locations from this report protects the privacy of the hospitals and communities within which this research was conducted. Ethics approval to conduct the study was first obtained from Athabasca University's Research Ethics Board (Appendix B) and then from four hospital Research Ethics Boards (REB) (Appendices C, D, E, and F) all located in Northwestern Ontario, Canada. Initially ethical approval was obtained from only one hospital but due to the low numbers of participants recruited, the sampling strategy was expanded to include two additional acute care hospitals and one rehabilitation hospital during the data collection phase of the study. The additional acute care hospitals were chosen based on the likelihood of there being a sufficient number of patients with TF from which to recruit participants as well as because these facilities were geographically located in the same general region and in the same province. The two additional hospitals were 700 and 1000 km away from the primary hospital site, while the rehabilitation hospital was located in the same city as the primary hospital. All institutional policies related to ethics, informed consent, and organizational impact on the hospitals were followed. Throughout the study, several changes to the research protocol were required and these changes were requested through Athabasca University and each hospital’s REB, all of which were subsequently approved.

There were no direct benefits to participants for participating, or any obvious risks. Participants were offered a $5 gift card following their participation in the study. One participant did experience emotional discomfort while discussing her experience during the interview but declined to stop the interview or accept a visit from a hospital counselor. Care was taken to avoid any undue influence on the element of voluntary participation given the relationship of trust and dependency the patients had with his or her health care providers. During recruitment, it was made explicit to the patient that the health services he or she received in hospital were not contingent on his or her participation, which was entirely voluntary.

When meeting with potential study participants, the researcher introduced herself as a Masters of Health Studies student and a registered Dietitian who was not practicing at the hospital. If the participant indicated that he or she would like to participate in the study, verbal instruction was provided to the patient (and family member if present) about the study purpose, procedures, benefits/risks, voluntary participation, confidentiality, ethics, study dissemination plan, the researcher's contact information and the right to withdraw from the study at any time up until analysis has begun. Each patient was provided with an information letter about the study (Appendix G) and given the opportunity to ask questions and seek clarification prior to the researcher obtaining consent (Appendix H). The ability to provide informed consent was assessed initially by the patient's nurse and health care team who kept the researcher informed. All recruited participants were capable of providing informed consent.

Participants were assured that their privacy and confidentiality would be maintained throughout the study. Private interview spaces were offered to each participant not assigned a private room, and all declined despite the researcher's suggestion and preference to complete the interview privately. All participants provided verbal consent to conduct the interview with family members, patients, and/or hospital staff present, stating that they were both comfortable speaking about their experience in front of others and with others knowing they were participating in a research study. It was made explicit to the participant that the researcher would not share the information provided during the interviews with any members of the participant's health care team or the participant's family members.

Participants provided, or were assigned, a pseudonym, which was applied to all personally identifying data, interview transcripts, and observation notes. All personally identifying data were kept in a locked filing cabinet in the hospital or researcher's home, and electronic data were maintained on the researcher's password protected personal computer, with the relevant files encrypted. Participants were informed that their demographic data and stories would be reported as unidentifiable aggregate data, and quotes, and that the final research report would be made available to them.

Data Collection

Inclusion Criteria

Adult, conscious, hospitalized patients capable of responding to questions were recruited if they were > 18 years of age, admitted to a medical or surgical ward of one of the acute care hospitals, had a tube inserted during the current hospital admission for the purposes of TF, and/or had received TF during their hospitalization. Patients, who were transferred from the ICU to a medical or surgical ward on TF, within one week of starting the therapy, were also included. Paediatric patients, intensive care unit (ICU) patients, or patients admitted to hospital while on home tube feeding were excluded.

Recruitment

The Dietitians of each acute care hospital agreed to participate in the study by screening all patients receiving TF and assisting with recruitment. Dietitians and Nursing staff of the medical and surgical wards of each acute care hospital were provided with brief teaching about the study purpose, inclusion/exclusion criteria, and recruitment protocol. Additionally the Dietitians and Nursing staff were reminded that a patient's decision to participate should have no bearing on their care in hospital.

The initial feedback from the Dietitians in regards to the recruitment protocol revealed that the term “short-term” TF was ambiguous. In discussion it became apparent that individuals who were started on TF in hospital with an impermanent intent would not necessarily be receiving TF for less than the usually defined 1-month period for short term TF. Furthermore, restricting recruitment to individuals who experienced TF for < 1 month would limit the number of potential participants as well as the depth and breadth of the acute care TF experience. Consequently, “short-term” TF was eventually excluded from the recruitment protocol explanation and has been removed from the title of this thesis. For this study, the population of patients who experienced TF is defined by the initiation of TF in acute care with an impermanent clinical intent but would not exclude individuals for whom the clinical intent may have changed during their therapy or during study participation.

Initially the Dietitians at each acute care hospital were asked to identify and approach potential participants for the study to ascertain his or her interest in participating prior to contacting me to complete recruitment. As this strategy did not result in adequate recruitment, the protocol was modified with REB approval, so the researcher was solely responsible for participant recruitment following screening by the Dietitian.

Following contact by the patient's Dietitian who provided the name and location of the individual, the researcher briefly visited each patient to introduce herself and to provide an overview of the study including the handout: “Information Letter for Participants” (Appendix G). The researcher returned several days later to ascertain the patient’s interest in participating or contacted them at home or at the rehabilitation hospital if discharged or transferred. If the patient stated he or she wanted to participate in the study, the researcher proceeded with explaining the study, answering questions, and obtaining informed consent as outlined in the “Ethical Considerations” section of this thesis. A number of patients requested that the researcher return to visit them several times before making a final decision to participate in the study. Each visit with patients was brief and friendly, with the patient guiding the conversation and eventually indicating his or her interest in participating. All requests to cease visitation were honoured and the researcher respectfully thanked each patient for his or her time and consideration of the study.

Recruitment of an adequate sample of participants from the population of acutely ill patients on TF was challenging. Less than five patients a month were screened for participation at each of the study sites. After 5 months the Dietitians at one acute care hospital withdrew as a participating study site stating they had been unable to screen patients due to heavy workloads. Hospitalized patients screened for the study frequently declined participation. While actively enduring their acute illness, patients indicated they did not want to discuss emotional aspects of their experience; a finding supported by the literature on patients’ illness experiences (Morse & Penrod, 1999). Efforts were made to recruit participants in the recovery stage of their illnesses, as this was when most were open to participating.

To improve recruitment, Dietitians at each of the study sites were again engaged to provide feedback on the recruitment protocol. Dietitians noted that a number of ICU patients who were transferred to the ward on TF could meet the inclusion criteria if the majority of their conscious TF experience had been on the ward. Thus the recruitment protocol was amended with REB approval to include ICU patients who were transferred to the ward on TF. Additionally, several potential participants were discharged home before completing the recruitment process or their interviews. Thus, the protocol was amended to allow the Researcher to request participants' home phone numbers and to interview them in their homes if necessary. These changes improved recruitment although a number of discharged individuals did not return phone messages while several others indicated they could not recall their experience with TF, or continued to face health challenges, which precluded them from participating. The data collection period was thus extended an additional eight months to increase the potential for adequate recruitment.

Sample

Convenience-sampling techniques were employed throughout the study given the difficulties with obtaining an adequate sample of participants within resource constraints. A total of 21 patients were screened for the study and 10 patients from two acute care hospitals agreed to participate. As concurrent data collection and analysis progressed, theoretical sampling techniques were employed by asking more purposive questions and re-interviewing two participants to provide in-depth clarification of emerging themes and to "flesh out" categories and subcategories of phenomena (Thorne, 2008, p. 92).

I was confident ending recruitment at 10 participants because of the depth and breadth of the data generated. The negative cases revealed unanticipated, important variations for the data set. Additionally, with sufficient repetition evidenced in the data as well as findings generated from purposive questioning, the completeness of the data set was deemed sufficient (Morse, Barrett, Maria, Olson, & Spiers, 2002).

Interview Process

Prior to beginning the first interviews, the researcher reviewed and discussed with the patient the study purpose, procedures, benefits and risks, voluntary participation, confidentiality, ethics, and researcher contact information. Consent Forms were signed (Appendix H). Participants were then asked if they would be willing to participate in a second interview if needed. Two participants refused, stating it would be undesirable to discuss their experience following hospital discharge because they wanted to put their illness experience behind them.

Following the signing of Consent Forms, demographic information was collected using the "Demographic Data Form" (Appendix I) to elicit contextual information about the participant and to serve as an "ice-breaker" (Vandall-Walker, 2006). Interviews were conducted individually and in person, were digitally recorded, and took approximately 25-60 minutes to complete. Three participants whose TF was started either in the ICU or in the operating room, were interviewed on a general medical or surgical ward because their TF experience extended to those care areas. The researcher transcribed two of the digitally recorded interviews and a professional transcriptionist transcribed the remaining interviews.

From the first introductory visit with a patient to the end of each interview, a professional and empathetic demeanour was maintained. Twelve years of experience as a clinician and counselor in the hospital setting, helped with effectively monitoring each patient's physical and emotional comfort to guide the interaction. Of the patients who chose to participate, most were quite amenable about having a visitor who was a researcher, and were open and comfortable discussing their experience. As previously mentioned, one participant became emotionally upset while describing her experience. This interview was paused and I offered to resume at a different time but the participant declined stating that she felt better talking with me about her discomfort. This participant also declined the offer of a meeting with a hospital counselor~~.~~

As described in the "Ethical Considerations" section of this chapter, all of the participants NOT in a private room, refused a private interview both insisting that they were comfortable speaking in front of patients, family members, and/or hospital staff, and with others knowing that they were participating in a research study. Hospital staff providing routine patient care interrupted two interviews. Participants declined the researcher's offer to leave and pause the interviews, instead she refrained from talking with the patient until the hospital staff left the room. The observations of the patient and caregiver interactions influenced the researcher's understanding of the patient experience and sensitized the researcher to ask other questions about interactions with HCPs. At the patient's request, one interview was conducted in the patient's home, four days after hospital discharge. In total, four interviews were conducted with a patient's spouse present at the patient's request. Although study questions were designed to elicit the individual patient's experience with TF, spouses often interjected with practical information about the patient’s care. The spouse’s comments provided clarification about the patient’s clinical course in hospital.

The first few interviews were exploratory in nature beginning with the broad, open-ended questions: “How would you describe your experience on TF while in the hospital?” and “What was that like for you…?”. The purpose was to reduce the structure of the interview, providing the patient freedom to tell his or her story while the researcher actively listened, without interrupting (Richards & Morse, 2007). Many participants responded to this initial question with an adjective describing how they felt about tube feeding, such as “horrible” or “awful”, while other participants responded by explaining their problems with TF and if it was beneficial for their condition. At times participants were prompted to elaborate by stating: “Tell me more” or “how did that make you feel?” encouraging a richer description of their experience. If the participant was not touching on the major points being investigated within the scope of the study or was not very responsive, they were prompted with additional questions generated from the literature on TF (Appendix J) to elicit more information. Some participants provided vague descriptions of their experiences while on TF focusing instead on describing their acute illness. To assist participants, additional questions were asked such as: “Can you please clarify that?” "Can you refer to a period during your hospitalization while on TF and describe how your experience was different then from now?”. These prompts assisted several participants with providing a clearer description of their TF experience within the broader context of their illness.

As the data analysis evolved, participants were asked more purposive questions to clarify and expand upon emerging categories and themes within the data set (Appendix

K). For example, following the first four interviews, questions were added to explore participants' perceptions about support following a comment that the Dietitian "didn't listen" when the participant described the discomfort she was experiencing with TF. This included inquiry into how participants felt supported and what was done to alleviate their discomfort, the role of information as a form of support, and differences among health care provider's practices. Additionally, questions were added to explore in greater depth, the experience of being unable to eat based on observations made during previous interviews.

As the theme ***NECESSITY*** and the categories of "support" and "coping" began to take shape, additional questions were added following the eighth and ninth interviews respectively, to flush out the properties of these concepts. The researcher inquired about participants' goals for their illnesses and the purpose of TF as well as characteristics that enabled coping strategies used while experiencing discomfort with TF. These questions were brought to new participants as well as to two others in a second interview, to generate broader variability in the data. Additionally, as the ID began taking on a more concrete shape, the early analysis was also discussed with these participants to determine if the analysis rang true to their experiences. This exercise helped to validate the central theme.

Six participants who provided rich data were contacted to complete a second interview. Of those six individuals, three had been discharged from hospital and two were deceased. Only two of these participants responded to the request to complete a second interview. The first respondent was interviewed in his home via telephone with his spouse on the line, approximately seven months from the first interview. This individual was no longer on TF and indicated good health and a “normal” dietary intake. The second respondent remained in hospital on TF and was interviewed in her private room three weeks following the first interview. Each interview lasted approximately 30 minutes. I transcribed the first respondent's interview directly into a notebook during the phone call while the second interview was digitally recorded and transcribed by myself.

Concurrent data collection and analysis revealed two major themes and one core theme that appeared to described the essence of participants’ TF experiences. The two major themes existed along a continuum of high to low TF ***DISCOMFORT*** and TF being an absolute to dubious ***NECESSITY***. The relationship between these two themes culminated as a question among participants: “Is TF necessary?” to describe their evaluation of whether TF was beneficial for their clinical condition while experiencing, at times, prolific ***DISCOMFORT***. A participant stated that for him, TF was “a necessary evil” and this phrase seemed to describe the conflict between the two major themes. When this phrase was contrasted with the negative cases, it was discovered that these participants did not always consider TF necessary, a realization that had a significant impact on their experiences. Thus ***A NECESSARY EVIL?*** became the central theme, presented as a question and was taken to the last two participants and two others in a second interview for verification.

When the theme ***A NECESSARY EVIL?*** was brought to participants, they commonly responded to the descriptor “evil”, by elaborating on the degree of ***DISCOMFORT*** they experienced with TF while reiterating the lack of nutritional treatment alternatives for their situation, “Yeah, I didn’t like it, but I had to do it.” These individuals all considered TF to be necessary for their illnesses therefore their responses to the central theme reflected their position on the continuum of ***NECESSITY*** as being an absolute rather than a dubious ***NECESSITY***. Participants who considered TF to be a dubious ***NECESSITY*** had only been involved with the first interview and had either passed away or did not respond to the request for a second interview.

Notes

Thorough notes were kept throughout the study to supplement the data generated through interviews and to provide contextual information for the analysis. Immediately following each interview, extensive notes were recorded in an electronic notebook on the researcher's personal computer. Care was taken to provide a detailed description of participants' personal environment and belongings within their hospital room or home, as well as behaviours, facial expressions, body language, interruptions, interactions with hospital staff or family members, and any other observations that seemed relevant to interpreting participants' experiences, such as their appearance. These descriptions and observations were helpful in informing the emerging analysis. For example, after the first few interviews it was noted that for participants who could eat, there were a large variety of food and beverage items placed on all their hospital furniture. "Why so much food and drink?" and "an example of family/friend support?" was written in the notebook with a reminder to add more purposive questions about resumption of eating and drinking and the provider(s) of the food items. Interview notes were summarized by asking the question, "What is going on here?" and thoughts were recorded at the top of each electronic table with the participant's transcript, units, and categories.

Additional notes were kept in chronological order in a paper journal throughout the course of the study reflected the researcher's emerging thoughts about the units, categories, and themes as well as any perceptions and biases held about previous personal experiences with TF. Later, as the categories and themes became more concrete thoughts were diagramed to establish patterns and relationships among the findings. Thoughts and ideas were also sketched on a whiteboard, which were recorded by taking a dated photograph and uploading this into a computer file. All of these note-taking methods were used to guide frequent personal reflection and discussions with the thesis supervisor, helping to shape the analysis and final ID. For example, following participants' explicit descriptions of the pain and discomfort associated with NG tube insertion, a personal note was made that suffering should be alleviated with different and improved NG insertion methods. By noting this bias, reflecting on it, and proceeding with more interviews, it became apparent that my personal perceptions could deviate from the meaning participants' attributed to their suffering, losing the richer description of the tube feeding experience.

Data Management and Analysis

In congruence with ID methodology, data analysis was inductive and iterative with the exception of demographic data (Appendix I). In ID, the researcher, not the steps, drive the comprehension of data, the synthesis of meanings, the theorizing of relationships, and recontextualization of data into useful practice (Morse, 1994). Similar to the reasoning process used by health professionals to compare individual clinical cases with all others they have encountered, data collection and analysis were concurrent (Thorne, 2008). Borrowing from the research traditions of psychology, phenomenology methods were used to come to know the data and allow the phenomena to "unconceal itself" (Wilding & Whiteford, 2005). I remained immersed in the data by repeatedly reviewing data from individuals to consider the meaning of the data, then returning to data collection with strategic purposive questioning. The constant comparative analysis techniques used in Grounded Theory methodology (Strauss & Corbin, 1998) were employed to allow patterns and relationships to become observable; a process that was augmented with the operations of unitizing and categorizing as described by Lincoln and Guba (1985). Repeated abstract theorizing interspersed with the time spent in the concrete reality of the clinical practice context resulted in findings constructed from the data as relationships among the category set became more evident.

The data analysis process included: knowing the data; moving from patterns to relationships; documenting analytic thinking; and generating a final analysis (Thorne, 2008). After data immersion began, the thesis supervisor guided the phases of data analysis, including reviewing the initial transcripts, the initial analysis and themes and categories identified, and advising on the evolving interpretation.

Knowing the data. The early phases of data analysis involved immersion in the individual case data to begin to inform interpretation. Each transcript was read while simultaneously listening to the recording, and making corrections to the transcript or adding to the interview notes. Each case was reflected on in relation to the question “what is going on here?”, and a summary of thoughts were recoded at the top of the transcript. These notes assisted in forming the initial impressions and included experiences that ranged from participants being “grateful” for a “necessary” yet uncomfortable therapy to being “uncertain” about the efficacy of TF while describing being “frustrated” to “relieved”.

Over several months, “space” was allowed for the phenomena to “unconceal itself” by being patiently passive towards the data (Wilding & Whiteford, 2005, p. 102). Meditation and reflection occurred during yoga practice, about what was being seen, heard, and interpreted about the phenomenon of tube feeding. Colleagues and the thesis supervisor were engaged with in regular conversations to explore their perspectives about the evolving interpretation. Attention would then return to the individual data sets and evolving categories and themes, to further contemplate, reflect, and write about the data, in the form of memos (Thorne, 2008). These heuristic tenets, allowed the researcher to become intimately familiar with the data by considering the individual words and stories of each participant to gain a deep understanding of that individual's tube feeding experience in relation to the collective experience being revealed as a result of the data set as a whole (Wilding & Whiteford, 2005).

Moving from patterns to relationships. Being open to patterns and relationships, becoming observable in the data involved, organizing the data into groupings, making sense of those groupings, and constructing a coherent whole using an iterative reasoning process. This involved remaining immersed in the data (Wilding & Whiteford, 2005) while utilizing Lincoln & Guba’s (1985) methods of unitizing and categorizing and Strauss and Corbin (1998) constant comparison analytic techniques.

Unitizing and categorizing. Following the completion of two interviews, the process of “unitizing and categorizing” began by reviewing each transcript while simultaneously listening to the recording and transferring “units” of information to a Microsoft Word table (Lincoln & Guba, 1985, p. 344). These units of information were participant words, sentences, or paragraphs that were interpretable on their own within the broader context of the study. Line by line, the meaning of each unit was considered and then assigned a descriptive code (consisting of a word, phrase, or participant quote), which was placed in the column beside the units. The early transcripts and initial coding were reviewed with the thesis supervisor who confirmed or provided guidance with respect to the early interpretations.

The process of categorizing units of information that were related to the same content, assisted the researcher in finding the “what” (Morse, 2008, p. 727) in the data. Categories were assigned following sequential review of each unit and descriptive code, considering its’ meaning, and assigning it to a section. Initially, category headings were written on post-it notes that were placed on a large piece of butcher paper taped to the office wall in an effort to "see" the thoughts and ideas being revealed. Each section or category was initially assigned a generic label to defer assigning meaning until further into the analysis (Thorne 2008). For example an early category was given the generic label “Tube Feeding is a Fix” as stated by the first patient to express his pleasure with the health outcome associated with receiving TF. A note was made to explore “expected outcomes” with subsequent participants. The label “Tube Feeding is Fix” was later changed to *Perceived Efficacy* with the sub-categories: *Belief in the value of nutrition* and *Knowledge of tube feeding*. This occurred as the properties and dimensions of categories were examined, which revealed a range of participant-described outcomes associated with TF based on their perceptions of the value of nutrition during illness and their knowledge of TF as a therapy.

Constant comparison. Constant comparative analysis involved comparing units to classify them as well as making theoretical comparisons to stimulate thinking about properties and dimensions and to direct purposive questioning (Strauss & Corbin, 1998). Individual units with participant identifiers were written on a post-it note and added under a category of similar content on the butcher paper. As new interviews were transcribed and unitized, the questions were asked: "does this unit look-alike" or "feel-alike" other units (Lincoln & Guba, 1985, p. 347)? Existing categories were then added to or new categories were created. A small number of miscellaneous units did not initially appear to fit into any of the early categories and these were put aside until later in the analysis.

When the majority of data had been placed into critical-sized categories the researcher began writing memos to record the properties and dimensions of each category. A broad propositional statement about each category was developed to capture the essence of the concepts within that category. Where necessary, concepts or categories in the literature were explored for comparative properties and dimensions in order to analyze the potential meanings of a concept (Strauss & Corbin, 1998). Each category was then analyzed for its properties to identify the dimensions of specific attributes along a continuum (Strauss & Corbin, 1998). The categories, sub-categories and associated properties and dimensions were then put into a Microsoft Word table with the associated units. For example, the category *Perceived Efficacy* was found to include the range of participants' beliefs that TF would effectively treat their condition. The property "efficacy" was classified by the type of outcome participants described then analyzed along the dimension of efficacious to not efficacious. This dimension was also examined along the property of "therapy stage", i.e. during or after TF therapy.

The sub-category *Knowledge of tube feeding* was also analyzed for different properties and dimensions. Knowledge was classified by “type” and then analyzed by the property “amount received” along the dimension sufficient to insufficient. Additionally, when it became apparent that some participants did not want information about TF during different stages of their illness, knowledge was examined with the properties “desire” and “stage of illness” along the dimensions low to high desire and early to late stage.

With the categories more clearly defined, each unit was reviewed to ensure its inclusion could be justified based on the definition of that category. Definitions were either refined at this point to harmonize inclusion of some units, or units were removed and placed aside as miscellaneous. When all data units had been assigned, the entire category set was again reviewed and the miscellaneous units originally placed aside were reexamined for inclusion in the categories. This exercise left only a few units that were discarded as irrelevant.

At this point, the categories could be compared and the relationships among them examined. Categories were reviewed for ambiguities, conflicts, and repetition to ensure internal homogeneity and external heterogeneity. Where required, corrections were made with respect to the placement of specific units (Lincoln & Guba, 1985). Some categories became subsumable under others, or were subdivided for homogeneity, and in other cases new categories were created to ensure heterogeneity and to round out the logic of the category system (Lincoln & Guba, 1985). Numerous diagrams were repeatedly drawn and redrawn to examine the relationship, as among concepts within each category and sub-category and to refine the patterns and relationships using the analytic strategies of extension, bridging, and surfacing (Lincoln & Guba, 1985). Extension involves inching towards the known to the unknown by building on information already acquired. Bridging involves connecting seemingly disconnected items of information in a relationship, and surfacing is used to propose new information that can be verified in the data when the logic of the situation demands it (Lincoln & Guba, 1985).

For example, participants described having goals for their illnesses. It was proposed that goal setting was important for participants in establishing the necessity for TF and for alleviating stress during illness (surfacing). By examining the literature about stress and coping during illness as well as by asking more purposive questions during subsequent interviews, the category *Personal Goals* was established. The categories: *Perceived Efficacy* and *Personal Goals* were bridged to illuminate why participants considered TF beneficial for their illness. With the assistance of the thesis supervisor, analysis inched from the known to unknown (extension) to discovering that participants' perception of therapy efficacy combined with their personal goals established the meaning of TF. Establishing the meaning of TF as beneficial not only affirmed the therapy as a necessity for their illnesses but also provided participants with the drive to tolerate TF discomfort.

To establish themes in the data, analysis continued to evolve with repeated immersion in the data and time spent reflecting on what was being interpreted. Memos were written and diagrams were drawn repeatedly on a whiteboard, to capture the potential relationships among categories. This allowed for interpretation of each category at increasing levels of abstraction. Themes began to emerge by thinking interpretively while repeatedly reviewing the audio recordings and transcripts while asking "what is this all about?" (Morse, 2008, p. 727). Additionally, themes became apparent from review of the repeated use of specific terms and phrases found in the data. “What am I seeing?”, “Why am I seeing this?”, “How does this relate to TF in acute care?”, and “How is this different from TF as an outpatient?”; these questions challenged the initial interpretations and influenced labeling and linking of the various elements (Thorne, 2008, p. 158).

With the thesis supervisor’s guidance, relationships were tested among categories and potential themes by placing them in matrices to assist with conceptualizing the concepts and factors that precipitated specific outcomes. The matrices helped envision whether potential themes went through the data to confirm their inclusion in the final analysis (Morse, 2008). Regular discussions with the thesis supervisor about the emerging analysis helped to ensure that data were being interpreted appropriately and always in relation to the research question. Eventually one central theme, two major themes and three themes emerged from the data.

Analysis led to the construction of the central theme ***A NECESSARY EVIL?*** to capture participants’ descriptions of their highly uncomfortable experiences with TF and their perception of whether it was necessary for their recovery from acute illness. Initially, the theme ***A NECESSARY EVIL?*** was described by the tentative themes “The Role of TF in Illness”, “Enduring TF”, and “The Value of TF”. However, with reflection and time spent in discussion with the thesis supervisor it became apparent that new themes were required because the logic of the situation demanded them (surfacing).

NECESSITY subsumed “The Role of TF in Illness” and “The Value of TF” because together these themes explained the factors determining a participant’s perception of TF ***NECESSITY*** (bridging). “Enduring TF” encompassed the outcomes or responses associated with the discomfort experienced during TF and did not fit as a major factor constructing participants' experiences. Rather it became apparent that the two major themes influencing whether TF was a necessary evil were participants' perception of TF ***NECESSITY*** and the degree of ***DISCOMFORT*** experienced. To move from the known to the unknown (extension), participants' responses to the TF experience were captured by examining the dimensions of ***NECESSITY*** and ***DISCOMFORT*** in a 2x2 matrix (bridging). By examining each participant as a case study it was discovered that their experiences could be explained by occupying different locations in the matrix. Thus four common responses to the experience of receiving TF in acute care were revealed as well as the influencing factors common to all of the experiences. The four common responses were: *relieved* (that a potentially beneficial treatment was being provided), *tolerant* (of the discomfort associated with TF), *indifferent* (to the ***NECESSITY*** of TF in light of minimal ***DISCOMFORT***), and *resistan*t (negotiating changes to TF or contravening care). The factors influencing the patient's experience as a ***NECESSARY EVIL?*** were captured in the themes: ***Trust*** (that health care providers were working in participants' best interest), ***Resilience*** (in response to TF DISCOMFORT and the overall illness experience), and additional ***Meaning*** beyond that of necessity (that TF will help participants attain their *Personal Goals*).

Data collection was terminated when there was a complex integration of the data set, the collection of data was not producing new information that pertained to the existing themes, and the sources of data and resources required to obtain them had been exhausted. The outcome of analysis was an integration of separate but inter-related themes grounded in the data capturing the adult patient's experience with TF in acute care.

Documenting analytic thinking. To assist analysis, document thinking and decisions, and formulate findings, chronological memos were kept in both a paper journal and electronically throughout data collection and analysis. Initially memos about early thoughts and impressions of the data were recorded to stimulate thinking. As more categories were developed, diagrams were sketched to examine what the major and sub-categories might mean individually, and in relation to one another, as well as the various processes, structures or schemes that might be illuminated about those relationships (Thorne, 2008). Memos on concepts in the literature were recorded to assist with theoretical comparisons and with assigning units (Lincoln & Guba, 1985). Over time, memo writing became more comprehensive. Extensive thoughts were recorded about what was being seen while continually asking: "Why is this here? Why not something else? And what does it mean?"(Thorne et al., 2004). In doing so thinking was expanded beyond the simple towards a complex conceptualization of the data. As the analysis took shape, memos were written in Microsoft Word to accompany power point diagrams that could be shared with the thesis supervisor and could be built on during these discussions. These electronic memos were maintained in a dated file folder as a supplement to handwritten memos.

The final analysis. To conceptualize the final analysis, comparisons were made between the themes, categories, and sub-categories with new and original literature to ensure findings were interpreted within the context of the wider body of knowledge. Examining findings with the related literature both within and outside the discipline of Dietetics, revealed new insights and diverse perspectives beyond the original theoretical platform for the study. Thus the final analysis is a holistic conceptualization of the patient's experience receiving TF in acute care that is grounded in rich data.

Ensuring Rigor

A credible ID study demonstrates theoretical, epistemological, and technical accuracy and relevancy (Thorne, 2008). The reliability, validity and credibility of the research findings were ensured by the researcher's responsiveness and by employing verification strategies (Morse et al., 2002).

Investigator Responsiveness

To ensure the reliability and validity of the study, strategies to ensure rigor were built into the research process. By following the iterative principles of qualitative research, errors were identified and corrected before they became a part of the developing model and subverted the analysis (Morse et al., 2002). Systematically checking data while monitoring and confirming the fit of data with the developing conceptualization ensured responsiveness (Morse et al., 2002). Being responsive in the use of verification strategies involved demonstrating analytic logic, interpretive authority, and representative credibility (Thorne, 2008).

Analytic logic. To record the inductive reasoning process, an audit trail was maintained and included: a) decisions about unitizing and categorizing data; b) the products of category and thematic synthesis, as well as construction activities; c) memos regarding rationale for decisions made; and c) the raw data (transcribed interviews and notes) (Vandall-Walker et al., 2007). The analytic logic of the interpretations was also demonstrated by the use of thick description of verbatim accounts from the raw data appropriately embedded in the findings section of Chapter 4 (Thorne, 2008).

Representative credibility. Qualitative studies with representative credibility make theoretical claims consistent with the manner in which the phenomenon was sampled (Thorne 2008). In borrowing the data analysis techniques from naturalistic inquiry, hermeneutic phenomenology, and grounded theory (Thorne, 2008) theoretical sampling techniques (purposive questioning and re-interviewing two participants) were used following careful consideration of the additional data or verification required to construct participants' experiences. Additionally, identification of negative cases and ongoing sampling to explore and confirm the range of individual experiences, contributed to the variety of perspectives found in the final thematic descriptions and ensured a representative sample within resource constraints (Creswell, 2013).

When approaching patients and conducting interviews, the researcher was always honest, respectful, and attentive to the detail informing her actions such as how she asked and responded to questions (Vandall-Walker et al., 2007). The researcher remained open to creatively incorporating new and existing literature and the suggestions and ideas of colleagues who reviewed the emerging analysis. Additionally, she remained flexible with data organization and coding as well as relinquishing any poorly supported ideas (Morse et al., 2002). Finally the researcher worked inductively, rather than from her a priori theories about TF and Dietetic practice (Thorne, 2008; Vandall-Walker, 2006).

Finding corroborating evidence to support the study findings and engaging an external critic added validity to the study by allowing for an understanding of, and accounting for, different perspectives (Thorne, 2008). Findings were compared with similar literature on various topics both within and outside the discipline of Dietetics (Richards & Morse, 2007). Additionally, the perspectives of the thesis supervisor, who is a registered nurse, as well as a hospital-based physician and Dietitian colleague was sought to illuminate different angles of vision about the constructed perceptions in the analysis (Thorne, 2008).

Interpretive authority. To reveal truths in the findings that were representative of participants’ views and external to the researcher’s biases (Thorne, 2008), reflexive journaling and active listening techniques were used during and after participant interviews. The researcher assumed a learner rather than an expert position on TF during interviews and when reviewing audio-recordings and transcripts, to allow for open and creative thought. In discussions with participants, their comments were repeated or paraphrased to verify what was heard, ensuring biases and experiences were not influencing the interpretations of their experiences.

A reflexive journal was kept to ensure that the researcher remained conscious of the biases, values, and experiences brought to the discussion about TF and the Dietetic profession. The potential influence on the construction of findings, conclusions, and interpretations was frequently considered while discussing with the thesis supervisor, allowing them to enable, rather than constrain the research process (Creswell, 2013; Wilding & Whiteford, 2005). As discussed in the **Interview Process** section of this chapter, early interpretations of the findings were brought back to some of the participants, who verified that the findings rang true to their experiences, thus supporting the interpretations (Thorne, 2008).

Verification Strategies

Verification is the process of checking, confirming, making sure, and being certain and includes strategies such as maintaining methodological coherence, sampling sufficiency, and an active analytic stance, as well as thinking theoretically (Morse et al., 2002).

Methodological coherence. Throughout the study, methodological congruence was maintained between the research question and the components of ID methodology (Morse et al., 2002). It was confirmed that the purpose of the study (capturing the patient's perception of the TF experience to inform clinical understanding) matched the research question (how do acute care unit patients describe their experience with TF in acute care). Additionally, the research question matched the method (ID), which matched the data (output of unstructured participant interviews) and the analytic procedures (inductive and iterative). By maintaining methodological congruence the conduct of this study was consistent throughout, generating a meaningful answer to the research question that will be useful to clinicians caring for the population of acute care adult patients receiving TF.

Sampling sufficiency. The inclusion and exclusion criteria created to inform sample selection were chosen to assist with congruence to the research question and were informed by the criteria used by other researchers working with this patient population and research question. The recruitment strategy was reevaluated and modified throughout the data collection period to ensure a broader population of patients was available for recruitment. Efficient and effective saturation of categories was ensured with quality data accounting for all aspects of the phenomenon, while minimizing waste (Morse et al., 2002). This was accomplished by extending recruitment to a maximum of 10 participants following the use of purposive questioning, conducting second interviews, and identifying relevant negative cases and variation within the data set to ensure a sufficient sample.

Active analytic stance. To ensure an active analytic stance the researcher maintained an interpretive authority while collecting and analyzing data concurrently (Morse et al., 2002). This iterative process involved moving back and forth between the study design and implementation procedures to ensure congruence with the research question, literature, and recruitment, data collection, and analytic strategies (Morse et al., 2002).

Thinking theoretically. Macro-micro perspectives of the data were maintained as was the emerging conceptualization by deliberately taking small steps forward, rather than cognitive leaps, while constantly checking and re-checking new data with that already collected (Morse et al., 2002). Remaining immersed in the interview recordings and transcripts while conducting the analysis, helped ideas emerge from data and these were reconfirmed in new data, giving rise to ideas that, in turn, were verified in the old data (Morse et al., 2002). This strategy combined with maintaining an active analytic stance supported the data analysis moving beyond the original theoretical scaffolding while comparing and contrasting possibilities (Thorne, 2008). Consequently the findings were built on a solid foundation from which insight about tube feeding in acute care have been illuminated beyond the self-evident (Morse, et al., 2002; Thorne, 2008).

Summary

In this chapter I have provided an explanation of the research approaches and methods used to recruit participants and to collect and analyze data in reference to the theoretical scaffolding required of an ID design. The decision to answer the research question: how do adult acute care patients describe their experience with TF, using an interpretive description approach informed each phase of this study. Additionally, the attention given to ethical matters and to ensuring rigor throughout this study, have been described in detail.

CHAPTER 4

FINDINGS

In this chapter, the findings related to participants' experiences with tube feeding (TF) in acute care are presented. Analysis of the data revealed both the context for, and the description of, participants' experiences. In reaction to the initial question: How would you describe your experience receiving TF in acute care?, all participants used a range of terms to describe the "discomfort" associated with TF. Additionally participants freely offered their opinions about the "necessity" of TF for their clinical conditions. When participants' understanding of these two terms was explored, attributes were revealed which informed the subsequent interpretive description (ID) of their TF experience in acute care as being ***A NECESSARY EVIL?*** (see Figure 1).

An overview of the ID of ***A NECESSARY EVIL?*** is provided first, followed by an explanation of the contexts influencing participants' experiences with TF in acute care, including: relevant participant demographic information including information about their various acute illnesses and the facilities where TF was experienced. The more detailed findings organized by different themes, and related categories which together describe the participants' experiences with receiving TF in acute care, constitute the greater part of this chapter.

A NECESSARY EVIL?:

PATIENTS' EXPERIENCES WITH TUBE FEEDING IN ACUTE CARE

Participants' descriptions of their experiences with TF in acute care were embodied within two distinct, but inter-related themes: ***NECESSITY*** and ***DISCOMFORT***. All participants experienced varying types and degrees of

DISCOMFORT (the “Evil”) while receiving TF. In light of this ***DISCOMFORT*** and within the context of their specific illnesses, participants questioned: “*Is tube feeding necessary?”*. Reactions to this question ranged from TF being considered a dubious ***NECESSITY*** to an absolute ***NECESSITY,*** and suggested that the core theme needed to be phrased as a question in order to embody their collective experiences of: ***A NECESSARY EVIL?*** For some the answer was a definite "yes", for others, "perhaps" or "I don't think so".

The relationship between perceived ***NECESSITY*** and ***DISCOMFORT*** influenced and was influenced by the inter-related themes of: the ***Meaning*** of TF to participants; ***Trust*** that Dietitians and health care providers (HCPs) were working in participants’ best interests; and ***Resilience*** in the face of TF ***Discomfort*** and their illness experience. The linkages among these themes influenced participant responses to TF being interpreted as *tolerant*, *relieved*, *indifferent*, or *resistant*, as depicted in Figure 1.

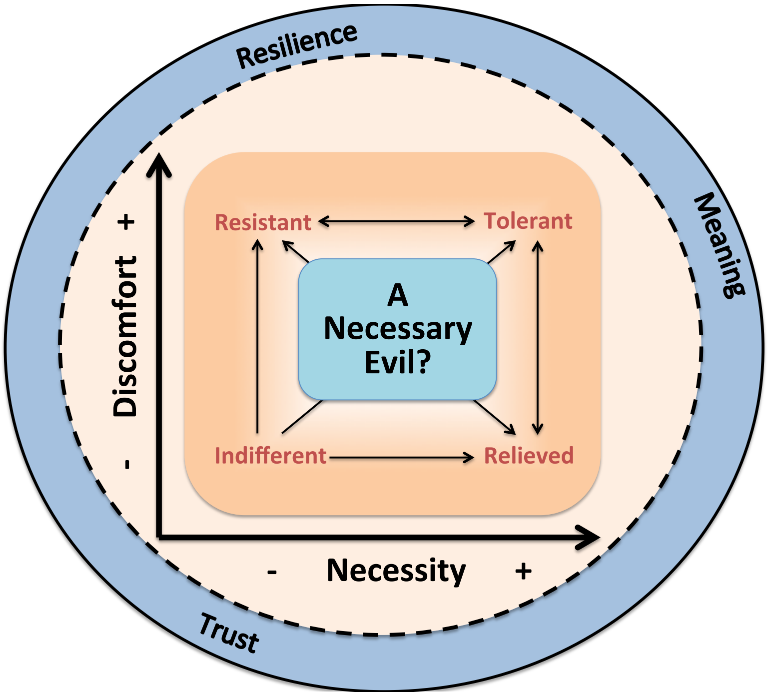

Figure 1. ***A Necessary Evil?***: Patients' experiences with tube feeding in acute care.

The first major theme entitled ***NECESSITY,*** reflects the participant's perception of how necessary TF was in aiding his or her recovery from acute illness. The ***NECESSITY*** for TF ranged along a continuum from participants having a strong conviction that TF was absolutely necessary, to questioning whether TF was or had been really that necessary. Throughout the TF experience, the influences on the perceived ***NECESSITY*** for this therapy included the degree and level of ***DISCOMFORT*** experienced and the additional ***Meaning*** participants ascribed to TF. While some participants were convinced of the ***NECESSITY*** of TF throughout their experience, others vacillated, deciding at the completion of the therapy whether TF had been necessary. Participants who felt TF was an absolute rather than a dubious ***NECESSITY*** expressed greater overall satisfaction with their TF experience.

The second major theme of ***DISCOMFORT*** includes participants' descriptions of the different types and degree of discomfort experienced. The categories associated with ***DISCOMFORT*** were related to: *Physical discomfort*, *Restrictive discomfort, The discomfort of* inconvenience *and fear*, and *The discomfort of eating and drinking challenges*. The discomfort experienced ranged from experiencing only one type of ***DISCOMFORT***, such as pain with nasogastric tube (NGT) insertion to experiencing all types of ***DISCOMFORT*** over the course of TF therapy. The degree of ***DISCOMFORT*** experienced by participants could be negligible to severe, and was influenced by the level of *Dietitian and HCP Support* provided and their ***Resilience*** in response to all they were experiencing.

The relationship between the range of perceptions of TF ***NECESSITY*** and the type and degree of ***DISCOMFORT*** experienced is presented as a matrix in Figure 1 to schematically depict the different responses participants had to their experiences with TF, from *tolerant*, *relieved*, or *indifferent*, to *resistant*. The internal arrows demonstrate the continuum of potential participant reactions to the TF experience. Any one participant could have experienced all of these reactions at different points in time during TF therapy, with no set progression from one response to another. For example, participants who believed TF was an absolute ***NECESSITY*** and who experienced a severe degree of TF ***DISCOMFORT*** were *tolerant* of the therapy. This is a reaction built on the additional ***Meaning*** ascribed to TF (beyond necessity) as being a beneficial therapy for illness recovery and health goal attainment, and the ***Trust*** held in the Dietitian's and HCP's decision to provide a highly uncomfortable, yet potentially beneficial therapy, all of which influenced each participant's ***Resilience*** in response to the experience.

When the value ascribed to TF as an absolute ***NECESSITY*** is coupled with minimal ***DISCOMFORT***, participants were *relieved* that they were receiving TF, and readily acknowledged the benefits of the therapy. With this reaction of relief, the ***Meaning*** given to TF as beneficial to illness recovery, and the ***Trust*** participants placed in their Dietitians and HCPs was validated and ***Resilience*** was not as significant a factor in their response to TF and all they were experiencing.

On the other hand, if the ***DISCOMFORT*** experienced was minimal or nonexistent and the ***NECESSITY*** for the therapy was considered to be dubious despite participants ***Trust*** in their Dietitians and HCP's decisions to initiate TF, participants were *indifferent* to the therapy, evidenced by a lack of interest in, and, understanding about, the purpose or value of TF, being more concerned with dealing with their specific illnesses symptoms. Participants assigned minimal additional ***Meaning*** to TF (beyond their perceptions of ***NECESSITY***) in terms of its importance to their recovery from illness and attainment of health goals and demonstrated ***Resilience*** in terms of the TF and their illness experience.

When experiencing a high degree of ***DISCOMFORT*** coupled with questionable faith in the ***NECESSITY*** of TF for his/her particular situation, participants became ***Resistant*** to TF and would contravene care. ***Trust*** in their Dietitians' and HCPs' decisions with respect to TF was questioned and no additional ***Meaning***, beyond their perceptions of the necessity of TF, was ascribed to the therapy for recovery from illness and health goal attainment. This response is interesting because it can be indicative of significant ***Resilience***, or a dearth thereof, in response to TF.

The relationship between the distinct but inter-related major themes of ***NECESSITY*** and ***DISCOMFORT*** explicated above, and including the themes of ***Meaning***, ***Trust***, and ***Resilience*** depicted as a matrix, informed the various responses participants' experienced as a result of receiving TF in acute care, leading to the interpretation that TF for this sample was about ***A NECESSARY EVIL?***

The Context of Patients' Experiences With Tube Feeding in Acute Care: PARTICIPANTS AND FACILITIES

Presented here is contextual information pertaining to the 10 individuals who were interviewed and includes information about their acute illnesses and a description of the facilities where they experienced TF. Where necessary, particulars of the participants' TF therapy have been described in detail. Additional contextual information is provided throughout this chapter with the explanation of ***A NECESSARY EVIL?***

Participants

Demographic information that is pertinent to this study is presented in Table 2 and includes: age, gender, education level achieved, admission diagnosis, indication for TF, study site and ward where TF was experienced, number of days on TF, the type of feeding tube, concurrent oral intake, days in hospital by time of interview, and participation in second interviews. An equivalent number of men and women between 40 and 90 years of age with academic attainments of high school to post-secondary degrees, participated in the study. All individuals declared themselves to be "Canadian" with the exception of one individual who stated he was of First Nations decent. Only two participants had previous experience with TF and the influence of this experience will be discussed, where applicable later in this chapter.

Table 2

Participant Demographic Information

Patient No.	Age	Gender	Education	Admission Diagnosis	TF Indication	Study Site	Hospital Ward	No. of Days on TF [a]	Type of Tube	Oral Intake		Days in Hospital	
										During TF?	Diet	First Interview	Second Interview
1	60-70	M	PC	Esophageal stricture	Same as diagnosis	1	Md	10	NG	N	M	21	D
2	50-60	F	HS	Cancer	Gastric obstruction	1	Sx	1	NG	N	CF	10	NA
3	40-50	M	PC	Gastro-esophageal tumour	Post-op esophagectomy	1	Sx	1	PEJ	N	NPO	4	NA
4	80-90	M	HS	Parkinsons Urinary retention	Dysphagia	1	Md	6	NG-PEG	N	NPO	6	NA
5	40-50	M	PC	Sepsis pneumonia	Mal-absorption syndrome & mal-nourished	1	I-Md	10	NG-PEG	Y	DAT	46	NA
6	40-50	F	HS	Post-op Bariatric Sx, Abdominal infection	Small bowel feeding	1	I-Sx	30	NJ	Y	FF	48	NA
7	50-60	M	PD	Liver transplant	Mal-nutrition	2	I-Md	160	NG	Y	DAT	150	NA
8	60-70	M	HS	Liver cancer	Dysphagia	1	MO	5	NG	Y	M	5	NA
9	40-50	F	PC	Cellulitis	Increased nutrient needs, hyper-metabolic	1 & 3	Sx	4	NG	Y	DAT	35	61
10	60-70	F	HS	Throat mass	Post-op tracheostomy	1	MO	7	NG	N	DAT	22	NA

Note. PC = Post-secondary certificate; HS = High school; PD = Post-secondary degree; Post-op = Post-operative, Sx = Surgery; Md = Medicine, Sx = Surgery, I-Md = ICU to Medicine, I-Sx = ICU to Surgery, MO = Medical Oncology; [a] Number of days on tube feeding prior to or at time of first interview; NG = nasogastric, PEJ = percutaneous endoscopic jejunostomy; PEG = percutaneous endoscopic gastrostomy; NJ = nasojejunal; M = Minced, CF = Clear Fluids, NPO = nil per os "nothing by mouth" DAT = diet as tolerated, FF = Full Fluids; D = discharged from hospital

The variation of self-reported admitting diagnoses and indications for TF noted in Table 2 indicate the heterogeneity of the sample, desirable because a variety of perspectives about the experience of receiving TF were revealed and not limited to homogenous influences such as the trajectory of a specific illness or disease, or a single hospital ward, and participants' care team. Participants' admitting diagnoses ranged from liver transplant, sepsis, cellulitis, gastrointestinal obstructions or infections requiring surgery, and chronic and/or terminal illnesses such as Parkinsons and Cancer. Related to the admitting diagnosis, were the indications for TF and included: dysphagia, mechanical obstruction or injury to the GI tract, malnutrition, and hypermetabolism requiring TF as a supplemental or a primary source of nutrition.

The duration of TF began when the therapy was offered by or initiated by Dietitians and HCPs, and ended when TF was no longer indicated. Participants were offered TF either before admission to hospital as a pre-emptive therapy for surgical recovery or shortly after admission to hospital. For others, TF was initiated at the discretion of the Dietitians and HCPs while participants were unconscious (such as in the operating room or ICU). All participants began their TF experience with tube insertion in hospital and with an impermanent therapeutic intent. With clinical changes, two individuals learned that TF would be required beyond their acute illness as a supportive therapy administered in a long-term or home care environment and thus their NG tubes were replaced with PEG tubes during the same admission. The resumption of safe and adequate oral intake and/or improvements in participants' clinical condition that precluded the need for TF, marked the end of the therapy for most participants.

Five participants had completed their TF therapy at the time of the first interview. With the exception of one of these five, who received TF for several months, the other four individuals received TF for less than or equal to 30 days. The other five participants were on TF at the time of the first interview and had been receiving the therapy for 1 to 10 days. One of these five participants remained on TF for a total of 21 days by the time of his second interview. Six of the ten participants indicated that a discharge plan was in place for either home or a rehabilitation facility. A seventh participant was discharged from hospital on NG TF for four days and was interviewed at home three days after TF had finally been discontinued.

Participants experienced TF with different types of feeding tubes. All but three of the 10 participants experienced NGT insertion, which was described as the most uncomfortable aspect of the TF experience. Two participants were fed into the jejunum, one via a percutaneous endoscopic jejunostomy tube (PEJ), inserted in the operating room, and the other via nasojejunal tube (NJT), inserted while unconscious in the ICU. One participant's NGT was inserted while unconscious in the ICU so no insertion discomfort was experienced. Nasogastric feeding tubes were observed to be the smaller-bore, flexible feeding tubes, such as a 10-12 French gauge and were described by participants as causing substantial ***DISCOMFORT*** throughout the TF experience. Participants fed into the jejunum experienced other forms of ***DISCOMFORT*** that will be described where applicable in the subsequent sections of the chapter.

Although the majority of participants were interviewed near the end of, or after TF therapy had been discontinued, most were able to reflect on and describe their experience throughout the different stages of their acute illness. For example, participants described how they felt physically and mentally prior to, during, and following the initiation of TF. This revealed a variety of reactions that influenced the range of experiences of receiving TF in acute care.

Acute illness is associated with substantial stress, which is compounded by the need for an aversive therapy such as TF. As described by one participant reflecting on the early period of her acute illness: "You know I've got a breathing tube…and a feeding tube. Holy smokes. Can it get any worse? So I was just trying to deal with all that." The difficulties in coping with the early stages of an acute illness were apparent among the individuals who were screened to participate in the study but who declined or delayed participation, because an interview would have been one more thing to deal with. Most of the 10 participants who did participate were entering the recovery stage of their illness or were preparing for discharge from hospital by the time they agreed to be interviewed. With the exception of the one participant who was struggling to adapt to her new reality with long-term TF, participants were calm and relieved to have the worst stage of their acute illness behind them. Participants repeatedly expressed that they wanted to participate in this study to share their experiences, to both give back and help others through the dissemination of this research. As kindly stated by one participant, "And whatever I can do to help you in your program…to help people in the future…I'm always like that…it's how we were born, born to be."

For participants, the stress and uncertainty associated with the initial stages of acute illness compounded by the inability to eat, was characterized by fear and anxiety. Participants described the requirement for TF as urgent, "But I had no choice. It was an emergency at that point." Participants relinquished control to their Dietitians and HCPs at this point, considering them experts who were qualified to make the best decisions for their care.

> *As the doctor says I need this, then obviously, I need it. There was no question in my mind. He said, "Well, think about it." Well, there's nothing to think about. "If you say I need it, and it's going to benefit me and help me heal faster, then sure-put it in.*

The desire for prescriptive care reflects the ***Trust*** participants had in their Dietitians and HCPs. As the uncertainty period of the acute illness began to pass, participants' desired more information and involvement in decisions about their care. ***Trust*** in their Dietitians and HCPs was influenced by the degree of support provided and influenced participants' experiences with TF, which will be discussed in the A ***NECESSARY EVIL?*** section of this chapter.

Facilities

General information about the three study sites included in the protocol was obtained from the participants and the data entered in the screening log. The study sites and hospital ward(s) where participants experienced TF are listed in Table 2. Several participants were transferred from an Intensive Care Unit (ICU) to a medical or surgical ward where interviews were conducted. Only those participants for whom the majority of their TF was experienceD on a general medical or surgical ward were included in this study.

Nine of the participants were interviewed at the primary study site, a 375 bed academic health sciences centre, and a tenth participant was interviewed in his home following a recent discharge from the second study site, a 198 bed community hospital. The third study site is a chronic care and rehabilitation hospital in the same city as the primary study site. This third facility was included in the study protocol solely to capture participants lost to transfer from acute to chronic or rehabilitative care. None of the participants were recruited from, or interviewed at, the third study site although one participant was transferred there for a period while on TF. Two participants experienced the early stages of their TF therapy at hospitals outside of the study protocol. The first participant was transferred to the primary study site from a small community hospital in his hometown (described as a 16 bed acute and long-term care facility) while the second participant was transferred to the second study site from a specialized care unit in a large tertiary care centre in Southern Ontario.

Participants who experienced TF at multiple hospital sites and/or on different nursing wards noted dissimilarities in their care that had an impact on their TF experience. Despite receiving care from a "team" of nurses, doctors, and dietitians at every location, participants described large, tertiary centres and specialized care units, such as ICUs, as "pampered homes" versus the smaller community hospital and general medical or surgical wards, described as " group homes". On general medical or surgical wards in the community and rehabilitation hospitals, participants found nurses to be "very busy" and less experienced with TF as compared to the staff in an ICU or at larger acute hospitals. Participants described experiencing new problems with their care, in smaller community hospitals, rehabilitation facilities, and on general wards, such as how NG tubes were inserted and maintained or how TF was delivered, impacting their comfort:

> *Everyone here knew how to do everything and there they had no clue [cries]. So flipping me around, pulling, flipping, prodding, I've got lots of sores inside now [points at NG in nose] because of the rubbing and…sorry [cries].*

Participants also described “fantastic” care and support from Dietitians and HCPs at all of the study sites and on different hospital wards. A notable difference was when participants described their care at the smaller community hospitals in their hometowns; they referred to dietitians and nurses as “friends” and expressed greater comfort with their care, “I was ok with people touching me to provide comfort. More so at [community hospital location] because the people there are a part of my community, I’m more familiar with them.” The clinical area and the characteristics and abilities of the Dietitians and HCPs influenced the type and degree of support participants’ received.

Contextual findings related to participants, and the facilities where they received TF influenced the interpretation and description of participants’ experiences with TF in acute care, described in the subsequent section. The heterogeneity of the sample, including the varied indications for TF, the type and location of the tube provided, and the location where care was received, created a range of responses to the TF experience that constructed the findings of this study as ***A NECESSARY EVIL?***

***A NECESSARY EVIL?*: Interpretive Description**

In this section, the evidence to support the idea of ***A NECESSARY EVIL?*** is provided including definitions and descriptions of the central, major, and other themes as well as the factors influencing them. Integrated throughout this discussion are participants’ responses to the experience of receiving TF in acute care in relation to the influencing factors.

The Cambridge Dictionary defines “a necessary evil” as something unpleasant that must be accepted in order to achieve a particular result (Cambridge Dictionaries, 2016). Tube feeding is the ‘unpleasant’ therapy that the participants in this study either accepted or struggled to accept as beneficial to aiding their recovery. The phrase "a necessary evil" applies to experiences where the participants disliked TF but accepted the therapy and the associated ***DISCOMFORT*** as an absolute ***NECESSITY*** for the treatment of their illness. To explain the experiences of participants who struggled to accept the ***DISCOMFORT*** and considered TF a dubious ***NECESSITY***, the phrase "a necessary evil" must be examined more closely.

The phrase "a necessary evil" derives from the principle of the lesser evil, which is often used in medical decision-making, and can be applied to acutely ill patients requiring TF (Spielthenner, 2010). Lesser evil reasoning holds that when faced with a situation in which one must choose between two courses of action, both of which will have undesirable outcomes, one should choose the course perceived to have the least undesirable outcome (Spielthenner, 2010). This form of reasoning accurately reflects the experience of many participants in this study. They held the perspective that given the context of their illnesses there were only two options to choose from: the first being a poor clinical outcome secondary to inadequate nutritional intake, and the second being TF ***DISCOMFORT***. Under the duress of illness, many participants accepted TF ***DISCOMFORT*** to be the lesser evil and thus it became a ***NECESSITY*** with potential for positive outcomes, "[Tube feeding] was necessary for my health…there was no other choice."

On the other hand, "boxing oneself in with two alternatives" (Spielthenner, 2010) is a pitfall to be avoided in lesser evil reasoning. In medical decision-making there are typically more than two alternatives from which to choose, with the right choice being the least evil of all the alternatives. This appears to reflect the experience of some participants in this study. Amidst profound ***DISCOMFORT*** with TF and/or doubt as to its benefit, these participants reasonably questioned if there was an alternative option that was less evil than both TF and nutritional deficiency. In this case TF came to be viewed as a dubious, rather than an absolute ***NECESSITY***.

As will be demonstrated in the subsequent sections of this chapter, the consideration of whether TF was a necessary evil during acute illness was foundational to the participant's experience and impacted his or her overall satisfaction with the therapy. Thus participants' descriptions of their experiences with TF in acute care are collectively interpreted as a question and are presented as the central theme: ***A NECESSARY EVIL?***

DISCOMFORT

When asked to describe their experiences with TF in acute care, participants most commonly responded by describing the negative physical and emotional impacts of TF. Collectively referred to as ***DISCOMFORT***, the different types of physical and emotional impact TF had on participants are described within the categories: *Physical discomfort*, *Restrictive discomfort, The discomfort of* inconvenience *and fear*, and *The discomfort of eating and drinking challenges* (see Figure 2.). All participants experienced discomfort

Discomfort

Physical discomfort
Restrictive discomfort
The discomfort of inconvenience and fear
The discomfort of eating and drinking challenges

Figure 2. Categories of the theme ***Discomfort***

and as a result, distress. The degree to which TF ***DISCOMFORT*** was unpleasant ranged from “it wasn’t too bad” to “it was absolutely horrible”.

Physical discomfort. The experience of having a tube in the body was very uncomfortable for participants regardless of their diagnosis or indication for TF. The *physical discomfort* associated with the feeding tube was greatest with NGT insertion no matter whether there had only been one or multiple attempts at NGT insertion. The degree of *physical discomfort* ranged from “uncomfortable” to “it was very painful!”

> *When they put the tube in. Oh that was terrible. [pause for 6 seconds]…I’ve never experienced anything quite like it. I could imagine it being like sticking a snake down a drain…if you can picture that. It, it was very un-uncomfortable…until it was in.*

For many participants, *physical discomforts* abated immediately following NGT insertion, “…it was a little painful at first, but once they got it up there, it was just like any other operation. When they tied it off, that was over, and away we went.”

After several days of TF, the tube became a painful irritant. Participants described discomfort in the nostril where the tube was located or discomfort at the back of the throat, “Because of it, my throat felt like there was razor blades cutting it at all times, and the mouthwash stuff, with the lidocaine...didn’t even cut it.”

The perception of *physical discomfort* was extended to include metabolic changes requiring insulin and thus the pain of injections, as well as uncomfortable gastrointestinal symptoms such as gastric reflux, nausea, vomiting, bloating, and diarrhea that participants attributed to the TF. Consequently, participants described feeling much more fearful and anxious because of the *physical discomfort* associated with TF, especially among those receiving jejunal feeding.

> *There was so much inflammation inside. I was a lot more anxious, yes, because of all the fluid I had on me. That was making it hard for me to breathe. So [the tube feeding] making me feel like I was full and bloated - made it twice as bad.*

Restrictive discomfort. The *restrictive discomfort* associated with TF due to the *physical discomforts* of TF and attachment to the tube feeding equipment caused frustration, related to participants' lack of mobility and need for personal control.

> *…[Having diarrhea in the hospital] at the time [was] terrible, because I couldn't leave the bed. So I was being changed every 20 minutes, so…ugh. You get used to it. But [I was] chained to the bed. And when I started therapy, or when I had to go to the bathroom, which is right beside the bed [laughs], you had to unplug everything or unplug the tube. And it was a whole procedure and I needed a nurse all the time to do it because I couldn't do it….because they will not let you disconnect it yourself. And sometimes you have to wait.*

As TF continued, participants desired more independence with TF to improve mobility or to ameliorate *physical discomforts*. Participants described understanding the hospital's restrictions on participants intervening with the TF equipment, but felt over time that they had become knowledgeable enough to control the feeding pump.

> *How could you screw [TF] up? So after awhile, I'd watched them long enough, and I'd see what they're doing and I'm not waiting 20 minutes for a nurse…click, click, click, click, click. And I would just reset [the feeding pump] myself. And they didn't like that.*

The discomfort of inconvenience and fear. The presence of the feeding tube and equipment created other discomforts for participants that were related to inconvenience and fear. The feeding pump was loud, interfering with conversation and sleep, a problem compounded by participants being forbidden to control the pump.

> *…oh, and the bell goes off and they don't come and turn…fix it before you're sleeping and, all of a sudden, "Bing, bing, bing, bing, bing." Something's wrong, it's empty or something like that.*

The most common inconveniences were those associated with the presence of the NGT, which was described as "always being in the way". Participants would accidently pull out the tube while they were sleeping or moving around in bed, or stick it with their fork when eating by mouth.

Participants were fearful about inadvertently removing the NGT because of the pain and inconvenience of re-insertion. If the feeding tube blocked, requiring removal, or if it was accidently pulled out and required reinsertion, participants became quite frustrated and discouraged. These emotions led to anger that was often directed at the nursing staff, followed by guilt.

> *[The tube] was sitting in the wrong place the first time, and the second time. And they needed X-rays, eight X-rays to make sure it was in place…Oh God, that was deflating, or whatever you'd call it. I was getting depressed. I got mad at the one nurse but I caught myself right away because I'm not like that. She's only doing her job the best she can and I apologized to her right away. I said, "Don't mind me. I'm just a little…" She says, "I'm there too Arthur"...Because she kept going back out and talking to somebody, and then she'd come back, "Well, we're going to try one more time". And that's when I'd get mad. So I blamed somebody out there; but, anyways, I'm not blaming anybody.*

Participants described multiple NGT re-insertions as a "drawback" of TF because of the time and effort spent to confirm tube placement with XRays. As noted by another participant who had multiple NGT insertions "I'll probably glow until I die!", indicating a degree of fear about all the exposure to radiation.

Discomfort associated with eating and drinking challenges. With TF, participants experienced different challenges with eating and drinking by mouth that for many was distressing. The properties associated with this category included being unable to eat or drink by mouth for short or long periods of time and the challenges associated with resumption of eating and drinking during recovery. Some participants were on supplemental TF and therefore could eat and drink throughout the therapy. These participants described being relieved because the comfort of enjoying food and beverage remained available to them.

> *And then I was like, "Oh, do I still get to eat?" [Laughs]. "Can I still have normal food?" And they're, "Oh yeah." So then, I went, "Okay, I don't care then." As long as I can still eat and enjoy the taste; that's one downfall with the feeding tube; you don't taste the food...I love my garlics, I love my salt and pepper…And yeah, I just like to be able to taste the food.*

There was a range of experiences expressed by participants who could not eat or drink by mouth. At one end of the range, some participants in the early stages of a severe illness lacked any appetite, stating food was unappealing. Participants who were not as ill, or for whom TF had not yet been initiated but were NPO, commonly expressed hunger, fear, and confusion with being unable to eat.

> *…for the first couple of days, I ate nothing. I think I had that much water in a cup [holds thumb and index finger close together]. That was it. That…was IT [emphasis]. I couldn't sip water because it caught back up to my nose. Well, that was terrible. I was starving; I was scared. You know, I didn't really know what was going on.*

Even while on TF, participants who were NPO (nothing by mouth) described in detail their desperate thirst and desire for water, with one participant mimicking the action of bringing a glass of liquid towards his lips. Participants described their unabatable thirst as "frustrating" and "horrible".

As TF continued, most participants noted that their hunger was satiated. For some who were told they would not be able to resume eating or drinking or for others who had gone without oral intake for a prolonged period of time, they described the experience of being unable to eat as a "disappointment". These participants described the social emptiness of being unable to dine with friends and/or shared details about foods they had enjoyed cooking and eating at home.

> *I can't have it anymore. Before I came in here I would have for breakfast a glass of cranberry juice…and I'd have a bowl of oatmeal. And I'd pour some cranberry juice on top of it…before I came in here [the feeding pump beeps loudly]…And now, I can't have any of that. [It's] hard. Can't eat a sandwich or have anything when I feel like it.*

Most of the participants recovering from acute illness eventually received a reduced volume of TF formula when they resumed eating and drinking by mouth. Resumption of eating and drinking was expressed as a small or large challenge depending on participants' clinical conditions and how long it took their appetite to return to normal. As summarized by one participant, learning to eat again was analogous to a "baby learning to eat solids" and the degree of difficulty and the time required was dependent on their clinical condition. For most participants with a shorter stay in hospital, the resumption of eating and drinking was described as straightforward, "It was all right. It kind of goes slow. The first sip I had, it felt weird. But after that, I was good." For others, weaning off TF was difficult because the challenges with resuming oral intake created a dependency on TF as an adequate source of nutrition. Many participants on TF for longer than a month experienced dysguesia, xerostomia, or olfactory changes that made eating and drinking a "battle".

> *Oh man, that was difficult. That was very, very hard. Uh, it [expels breath]…not the point of not eating…it was the point that everything tasted like crap. It…the food just had no appeal, no taste, I couldn't swallow it, the smell was enough to make me want to jump out the window.*

These participants described feeling "frustrated", and "angry" with the new challenges presented with resumption of eating and drinking. As eating and drinking improved, participants stated they felt renewed belief that they would recover. Other participants on TF for a shorter period of time were less dependent on TF but remained challenged by dysguesia, the lack of variety and appetite for hospital food, as well as dietary restrictions interfering with food preferences.

The major theme ***DISCOMFORT*** encompasses several of the challenges with TF that were distressing to participants throughout therapy. Being a highly unlikeable therapy, participants' responses to TF ***DISCOMFORT*** ranged from being *tolerant* to *resistant* to the therapy, depending on how necessary they believed TF to be in their eventual recovery. The degree of ***DISCOMFORT*** experienced was influenced by the support received from Dietitians and HCPs, by the additional ***Meaning*** TF had for them in relation to recovery and health goals and by their ***Resilience*** in response to all they were experiencing.

NECESSITY

Participants' perception of the need for TF as an aid to their recovery revealed the theme of ***NECESSITY***. Perceptions about the ***NECESSITY*** for TF fell along a continuum from being considered an absolute ***NECESSITY*** to questioning the need and considering it a dubious ***NECESSITY***. Participants who perceived TF to be an absolute ***NECESSITY*** were generally convinced that TF was beneficial for recovery from illness, whereas others were uncertain and thus considering TF as a dubious ***NECESSITY***. The participant's position on the continuum of perceived ***NECESSITY*** could move at varying points throughout the therapy or could remain the same depending on a number of influencing factors.

Most participants were convinced of the ***NECESSITY*** of TF throughout and following therapy. They were confident that TF would be or was valuable to their recovery and thus were highly *tolerant* of the ***DISCOMFORT*** experienced, "*I didn't like* *it, but it was a necessary evil because I wasn't eating. So I knew I had to have it, so I accepted it."*

Other participants believed TF was a potential ***NECESSITY*** for their illness but became uncertain while experiencing ***DISCOMFORT***. Experiencing doubt as to the benefit of TF coupled with significant ***DISCOMFORT*** influenced some participants to exhibit *resistant* behaviours, both positive and potentially negative, from negotiating changes to their TF regime (positive), to physically removing the NGT, or refusing to continue with the therapy (potentially negative).

> *But then I was just absolutely frightened when I started vomiting and everything. It totally changes…like, "[Tube feeding] is not going to work." [laughs], "Oh, this isn't going to work, for sure...I wouldn't let them do it anymore. There's no way. It wasn't absorbing, obviously.*

Other participants, such as those who were under substantial stress in the early stages of their illness, were unsure about the ***NECESSITY*** of TF. Some of these participants never came to recognize TF as beneficial, while most became more certain over time as they began to improve and appreciate the role TF had in their recovery.

> *I had a lot to take in at that time, though…I really wasn't in the mood to be asking any questions…knowing that I'm getting the nutrients that my body requires to get…now, I feel good about [tube feeding].*

The ***Meaning*** participants ascribed to TF explains why they considered TF to be a ***NECESSITY*** (or not) amidst what was appraised as an uncomfortable, and at times, highly challenging therapy. ***Meaning*** went beyond the appraisal of whether TF was necessary or not and encompassed their efforts to find meaning in their experience to help them remain hopeful and cope.

Meaning. The theme ***Meaning*** is defined as participants' interpretation of TF as a therapy that would help them to attain their *personal goals* - beyond their perceptions about ***NECESSITY,*** the major theme with which this theme is entwined. Having appraised TF as an aversive therapy, participants looked to the ***Meaning*** of TF in order to develop a *hopeful outlook* as a way to *cope* with the ***Discomfort***. The ***Meaning*** of TF ranged among participants from a therapy providing hope to one that did not provide hope and could change for participants throughout the therapy if the burden of ***DISCOMFORT*** became intolerable or if they gained sufficient knowledge about TF. The ***Meaning*** participants ascribed to TF are described by *Personal Goals*, *Perceived efficacy of TF* and the sub-categories: *Belief in the value of nutrition* and *Knowledge of TF* (see Figure 3).

Meaning

- *Personal goals*
- *Perceived efficacy*
    - *Belief in the value of nutrition*
    - *Knowledge of TF*

Figure 3. Categories and sub-categories of the theme ***Meaning***

Personal goals. While experiencing a highly stressful illness, all of the participants established meaningful goals to focus their work toward recovery. Participants spoke at length about being motivated to achieve goals that centered on a future with a resolved or stable illness. Goals varied based on participants' admitting diagnosis. For example, participants' admitted to hospital with a recent diagnosis talked about wanting to "get healthy quick", "heal", and "survive" whereas participants with a chronic or terminal illness indicated broader goals that ranged from wanting to "just get out of the hospital" to "taking life one day at a time". Chronically or terminally ill participants discussed their desire for “normalcy” in life and included desires to eat and drink again by mouth, prepare meals for friends in their homes, or complete household projects.

Regardless of the type of goal, participants were committed to attaining them. Thus participants looked to therapies that they attributed to providing hope, such as one participant with terminal cancer who’s goal was to get home and have a dinner party with friends:

> *I had hope that I was going to be able to get some nutrition. There’s always something good. Definitely. Because [tube feeding] totally gave me hope. Because I didn’t know what else to do. I guess neither did they.*

The value of TF in enabling goal attainment was dependent on participants’ perception of TF efficacy.

Perceived efficacy. Perceived efficacy refers to the range of participants’ beliefs that TF would effectively treat their condition. Participants’ beliefs ranged from TF being efficacious to doubting its benefit. The more efficacious TF was perceived to be, the more committed participants were to tolerate the therapy and the more grateful they were for having received it. The participants’ beliefs about TF efficacy were informed by their *beliefs in the value of nutrition* and by their *Knowledge of TF*.

Belief in the value of nutrition. Nutrition, provided in a medicalized form such as TF or as food and beverage eaten by mouth, was expressed as highly valuable to improving or maintaining participants’ physical and mental health. As previously explained in the *Discomfort associated with eating and drinking* category, participants described their psychological need for food by the emotions felt when they could not eat. Nourishment was described as “important to human life” so when unable to consume adequate nutrients by mouth, participants were open to receiving nourishment from TF. Belief in the physiologic benefit provided by an artificial nutrition support regime, such as TF, ranged among participants as “keeping me alive” to maintaining or improving measures such as healing wounds and increasing body weight and strength.

Belief in the value of nutrition was also defined by the properties of immediacy and amount. The urgent requirement for nutrition was evident among participants who described starvation as abhorrent. Participants, especially those who were underweight or who had been unable to eat for a prolonged period, were fearful of the consequences of starvation, describing an immediate need for TF to alleviate their fears.

> *I was scared, very scared, because I was going to die of no food…Because you’ve already got a disease. And then, on top of that, then you can’t eat. It’s like, ‘What’s going to kill me first here?’*

Once initiated, participants were relieved to be receiving nourishment through TF enabling them to be hopeful.

> *It’s just more of a relief that I’m getting something into me. The first four days were awful. I really felt hungry and once I got [the tube feeding], I knew that I was getting something, and just was going to get better.*

Other participants such as those who began their hospitalization in the ICU or who were observed to be, or described themselves as, overweight, were less inclined to describe an immediate need for nourishment or relief with receiving TF, “With as sick as I was…does everybody who’s as sick as I was have food…TF? I don’t know. I’m sure the answer is, ‘No’?”. Some of these participants expressed a desire to lose weight during their acute illness and described being content with smaller amounts of nourishment than what was prescribed by their Dietitians and HCPs.

The participant's perception of the amount of required nourishment ranged from "some" is beneficial to the amount prescribed by the Dietitians and HCPs as beneficial. "Some" nutrition was defined by those participants as less nourishment than was prescribed by their Dietitians and HCPs. Participants' comfort with "some" nutrition was evident by their descriptions of multiple interruptions to and prolonged TF delivery delays within a short therapeutic period, yet attributing positive clinical outcomes to the therapy. Some participants, who believed "some" nutrition was beneficial, were less inclined to tolerate the Dietitians and HCP's prescribed TF regime if it was causing ***DISCOMFORT***.

> *Well, I guess because I wasn't able to eat or drink anything, they needed to get nutrition in me somehow, even just little bits…But I think that they didn't need to use it, like they did. Length of time, yeah…like, maybe a couple hours during the day here and there, not 24 hours a day…*

Other participants, such as those on TF for several weeks, felt it was important to receive the Dietitians and HCP's prescribed amount of nutrients. Ensuring the TF regime was provided, as intended, was important to these participants regardless of the ***DISCOMFORT*** experienced.

> *So they couldn't modify the amount of nutrition that they were giving me. Plus, I was also getting extra water through the tube and other…and stuff…because I have a bed sore, so it came in handy for more than one thing. [It was important] to get the calories and everything else that I needed.*

Believing nutrition, in different forms and amounts, had value during acute illness was influential in helping participants determine if TF was efficacious. Participants also had to develop an understanding of TF, which was reflected in their knowledge about the therapy.

Knowledge of tube feeding. Finding ***Meaning*** in TF required that participants understand TF as a therapy, including its role in providing nourishment and whether or not it would be efficacious. Participants' knowledge of TF was described by two properties: the first was the desire for TF knowledge, which ranged from being undesired to desired and was dependent on the stage of the participant's illness; the second property was the type and amount of TF knowledge provided by Dietitians and HCPs, ranging from perceptions that it was sufficient to perceptions that it was insufficient.

In the early stages of acute illness, especially among those who were recently diagnosed or who were critically ill, participants described being under profound stress and expressed little desire for information about TF.

> *Yeah, I think they gave me a pamphlet or something, but I'm not sure what they did. I wasn't in that good a state of mind when I found out I had the throat, tongue, and liver cancer all at the same time. I wasn't really paying attention to anybody. But I'm pretty sure I can remember them saying how [tube feeding] was going to go and that. But, I don't know if I listened [laughs].*

Participants also described being unable to "remember too much" information provided in the early stages of their illness. As stated by one participant, "Some things you don't want to remember." Consequently, participant's understanding about of TF and his or her perception of the efficacy of the therapy were limited. These participants were described as being *indifferent* to TF while they passively accepted care from the Dietitians and HCPs and processed the meaning of their acute illness.

As the therapy continued, participants began to desire more information about TF. Participants' Dietitians, HCPs or family members usually offered information such as the purpose for TF to provide nourishment. However, many participants, especially those in hospital for a short period, described gaps in their understanding about TF. The most common information desired was: "how does TF work?", "what to expect?", and "how long will it last?". As stated by one participant, receiving answers to these questions helped him to feel confident and prepared:

> *Yeah, at least I'd know what was going on. You know, why it's there, what it's doing, why I need it. You know, it's not just something they hooked up and I have no idea what's going on.*

Participants who were sufficiently informed about TF described comprehending the therapy and expressed more comfort and less anxiety about their situation.

> *The Dietitian did come in and just kind of explained to me a little bit, what the feeding tube was all about. Because, honestly, I didn't know…how big…what it looked like. It was a little bit scary and intimidating at first, but once she explained it to me, "This is how it works", I wouldn't feel much discomfort, or I shouldn't. And it's true, I don't.*

With a good understanding of TF, many participants established TF as meaningful to their recovery and could move from being *indifferent* about TF to *relieved* that they were being nourished. While for others the ***NECESSITY*** for TF continued to be dubious.

In the presence of ***DISCOMFORT*** with TF, participants who questioned the value of an aggressive, prescribed TF regime, expressed a desire to know specifics about their TF regime such as the amount of calories being provided. Once received, some participants used this information to assess and formulate conclusions about their nutrient needs, as not all that necessary. They became *resistant* to the prescribed TF regimen, demonstrated by either negotiating changes to (a positive response) or contravening TF care (a potentially negative response) when they experienced ***Discomfort***.

> *It was like, 30 ccs an hour, which is like two tablespoons. I just sort of worked it out in my head what I was getting. I knew it was roughly 1100 calories. That's a lot for someone who has just had bariatric surgery and would probably have that at a mealtime, three times a day…I've asked the nurses to turn it off a few times…when I realized that I could ask. And…they would.*

In some cases, participants who lacked sufficient or appropriate information about TF expressed confusion, anger, and frustration with the therapy.

> *Other than the fact that I was going to have a tube in my stomach…I know nothing about tube feeding. My doctor sort of said, you have to have it or you're going to starve to death…How did that make me feel? Terrible. I still don't understand it…it's running all day long you know, they start early in the morning, and they're feeding me all damned day.*

Some participants pointed out that they were uncomfortable asking their Dietitians and HCPs questions about TF, "I generally don't ask questions…when I chat with the Doctor, "What are you saying?" I don't know [laughs]." Whereas other participants had trouble speaking and were reliant on Dietitians and HCPs to offer sufficient information or to patiently wait while the participant articulated his or her questions. Participants who desired information about TF but were unable to receive it were challenged to accept the therapy and thus find helpful ***Meaning*** in it.

Participants requested information about TF and their specific TF regime be provided in brief written form and/or through ongoing verbal communication with their Dietitians and HCPs. As summarized by one participant:

> *Tubal feeding can't be made more comfortable but it could be made more understood, what you're doing, trying to do. Write it up, wrap it up, and show it out.*

The Dietitian's and HCP's provision of adequate and timely information was described by participants as a form of support and will be discussed in the ***Trust*** section of this chapter.

Participants' understanding of TF combined with their beliefs about the value of nutrition during illness formed their perception of TF efficacy. Participants defined TF efficacy by the outcomes attained at different stages of their illness. Participants whose

TF therapy was in progress described a range of physical outcomes including ***DISCOMFORT*** that was perceived as impeding their clinical progress to beneficial effects.

> *Oh, [tube feeding] has been great. I felt great after they started, the next day. It's like a boost because I wasn't getting anything. I just sort of got a little more energized. I wouldn't start jogging around the place [laughs] or anything, but…*

Other participants described TF as "keeping me alive" or "keeping me at my weight" while they received the therapy. For those no longer on TF, the efficacy of the therapy ranged from being perceived as being efficacious to not being efficacious. Participants who described TF as efficacious commonly perceived that it had saved their lives, "I almost died. And the food they gave…the tube feeding, it saved my life." These participants were very satisfied with their health outcomes regardless of the ***DISCOMFORT*** experienced, "It's hard to believe the food coming through the tube in liquid form can keep you living for a while. The advantage is once set up it worked! I'm grateful it was there." Other participants did not express satisfaction with the therapy, considering TF to be a potential disadvantage to their recovery, "I honestly don't think tube feeding was necessary…would it have made my progress slower? Hard to say, it's quite possible."

Participants evaluated the efficacy of TF against the probability that it would help them attain their *personal goals* thus establishing the ***Meaning*** of the therapy. Those who assessed TF as likely to be efficacious found ***Meaning*** *in* TF as a therapy that would enable goal achievement and was therefore an absolute ***NECESSITY***. These participants described feeling *relieved* that they were being adequately nourished and could be tolerant of the ***DISCOMFORT*** experienced.

> *If it's going to help my legs heal, help me get better, help me walk again, help me get out of here, of course, then, it's a necessity. So regardless, if it's a little uncomfortable, so what? Suck it up.*

For some of these participants, the ***Meaning*** of TF as a desirable therapy was threatened by intolerable ***Discomfort***. For example, with excessive vomiting or prolonged pain and inconvenient repeated NGT reinsertions, participants questioned how the therapy could lead to goal attainment and they doubted the ***Necessity*** of TF. Other participants with a lack of understanding about the therapy and/or the value of an aggressive artificial nutrition support regime, never established the **Meaning** of TF as beneficial. When a positive ***Meaning*** was threatened or was non-existent, the stress of the experience increased, and fear, frustration, and anxiety rather than hope were the predominant emotions experienced. These participants reacted by being *resistant* to TF as ***Discomfort*** increased.

Maintaining or restoring the ***Meaning*** participants ascribed to TF throughout their experiences influenced and was influenced by the type and degree of support provided by their Dietitians and HCPs and by participants' ***Resilience*** in response to all they were experiencing. Support influenced the degree of ***Trust*** participants placed in their Dietitians and HCPs. With ***Trust***, participants could feel confident and secure in the ***NECESSITY*** of TF and in their care.

Trust. ***Trust*** is defined as participants' confidence that they could rely on their Dietitians and HCPs to be competent and supportive with respect to TF care. Given the high level of uncertainty associated with their acute illnesses, ***Trust*** in the care provided by Dietitians and HCPs was fundamental to reducing participants' anxiety and influenced their reactions to the TF experience. ***Trust*** in Dietitians and HCPs appeared to build iteratively for most, as the experience of receiving TF unfolded. For some, there was a decrease in the ***Trust*** in Dietitians and HCPs. The categories and sub-categories related to Trust are outlined in Figure 4.

Trust

Prescriptive care

Dietitian and health care provider support
- *Being instrumental*
- *Providing information*
- *Being collaborative*
- *Providing emotional support*

Figure 4. Categories and sub-categories of the theme ***Trust***

Prescriptive care. In the early stages of TF, most participants assumed their Dietitians and HCPs were competent and could be trusted. Participants commonly described having "no choice" in the decision to initiate TF. This was a reflection both of their perception that the need for TF was emergent and for the ***Trust*** they had in their Dietitians and HCP's competence to select the most necessary therapy for their condition. By relinquishing control to their Dietitians and HCPs, participants described themselves as being *indifferent* to TF. Participants commonly expressed that their Dietitians and HCP's had the expertise to decide if TF, and the prescribed TF regime, was best for them, reflecting acceptance with a prescriptive style of care.

> *Ah, well, I don't even know how much 42 milliliters is, or [laughs] so-...yeah, I was comfortable with what they do here. What they say is...I hope they're right. Yeah, because they're trained to do it, and we're not.*

Dietitian and health care provider support. As TF continued, the decision to ***Trust*** Dietitians and HCPs was weighed against participants' evaluation of how their TF treatment was proceeding. This included considering factors such as whether TF was efficacious, how much ***DISCOMFORT*** was experienced, as well as by the availability of *Dietitian and HCP support*. Perceptions of *Dietitian and HCP support* ranged from it being "amazing" to "not very helpful" and included the sub-categories: *being instrumental*, *being collaborative, providing information,* and *providing emotional support*. ***Trust*** not only influenced how necessary participants believed TF to be, but affected their perception of, tolerance to, and ***Resilience*** in response to the ***DISCOMFORT*** experienced.

Being instrumental. The most common reaction to the question "How would you describe the support you received from your health care providers?" was in regards to the instrumental support Dietitians and HCPs provided. Participants were appreciative of the basic TF support provide by their Dietitians and HCPs, such as setting up the feeding pump and ensuring the delivery of TF.

> *The Dietitians were always on top of [the tube feeding]…The Dietitian dictates to the nurses what needs to be done and writes out a form. She made sure that it was, followed. She checked the food, she checked the fridge, and she checked I was getting everything. She checked how much was going in and out. So she knew when there was a mistake being made, and she corrected it.*

The Dietitian's role in the provision of instrumental TF support was not always clear to participants. "She [Dietitian] had [a role]? Did she? I thought they would just go around and ask people what they want to eat." Regardless of participants' understanding of the Dietitian's role, those in hospital for a short period described feeling confident in the TF care provided by their Dietitians and HCPs, "It makes me feel good, everything is looked after". Those in hospital for longer periods became knowledgeable of care routines and became concerned when there were inconsistencies in their care such as with

NGT maintenance to prevent nasal pain or tube blockages, and the provision of the TF regime.

> *…And it's up to the nurses to read [the tube feeding orders] and follow it. I find the nurses were very busy. And instead of everyone reading the thing, they'd sometimes just follow the leader and sometimes not get it correct. There were a few discrepancies when I was there. And the Dietitian had to fix it…*

The provision of consistent and attentive care was an aspect of instrumental *Dietitian and HCP support* that increased participants' confidence in their care providers and reduced their anxiety.

Another important aspect of instrumental *Dietitian and HCP support* was whether Dietitians and HCPs appeared to work as part of an inter- and intra- professional care team. Participants described a range of professional behaviours that either created frustration or made them feel safe and supported. For example, participants viewed care inconsistencies between professionals as a barrier to their recovery.

> *It frustrated me a little bit that the [ward] Dietitian and the [specialist] Dietitian weren't working together…it didn't make sense why every meal that came up was pudding. I still think that my meals were not set properly in the computer system.*

When participants felt that their Dietitians and HCPs were working as part of an interprofessional team they described greater confidence in their care.

> *They let me know that they're all here as a team, or showing me that they are a team and that they all work together and everyone has their input and information about [tube feeding], and their own way of explaining it to me; how it works and how much. And so it was nice. It made me feel more comfortable and relaxed about the situation because they all came to a common conclusion, that it's for me and my benefit.*

Being collaborative. Participants described regular communication with their Dietitians and HCPs as supportive. Although participants accepted a prescriptive care approach in the early stages of TF therapy, most desired a collaborative communication style with their Dietitians and HCPs when their condition stabilized. Collaborative communication was described as being kept informed by Dietitians and HCPs, being heard and sharing in decision making, while working together to provide good care. “Like, the doctor would come in, the nurse would say, “Okay, he’s done this, this, this, this, this. I recommend this;…what do you think?” And then we would all discuss it.”

Sharing in the decisions made with respect to their TF care empowered participants by enhancing their understanding of TF, promoting a sense of control, and engendered greater ***Trust*** in their Dietitians and HCPs. For example, participants described feeling they had more control of their situation if they could ask their Dietitians or HCPs to adjust the TF regime when experiencing ***DISCOMFORT***, although this option was not always made clear to participants, “It would have been helpful to know that I could have asked earlier!”

Participants who had prior experience with TF were noted to be more assertive than the other participants with respect to participating in shared-decision making practices about their TF. These individuals drew on their previous knowledge of TF to have effective discussions about their TF regime with their Dietitians and HCPs and make decisions that fit with their individual desires and beliefs.

> *They were going to put [a PEG tube] in my stomach, and I said, ‘No, no, you’re not doing that.’ Because I had one already and I didn’t like it, and I didn’t intend to be here that long.*

Participants who felt that their Dietitians and HCPs involved them in decisions about their care described feeling more comfortable with TF and *relieved* that they were receiving the therapy. Additionally, these participants were able to be *tolerant* of TF Discomfort because they could ***Trust*** their Dietitians and HCPs to address their concerns while sharing in their confidence that TF was the best therapy for their condition. In contrast, participants who did not experience collaborative care described greater frustration and anxiety with their TF experience.

> *I think the most frustrating part was them not believing me when I was telling them that [tube feeding] was making me feel that way. They kept saying, "It's not possible." …Like, the Dietitian wasn't as easy to work with. She was the one that kept telling me it's not possible that I feel bloated and full, and there's not enough going in me for me to feel that. But that's exactly what I was feeling.*

Consequently, these participants had little Trust in their Dietitians and HCPs and would question the ***NECESSITY*** for TF leading to *resistant* behaviours when experiencing ***DISCOMFORT***.

Participants also appreciated their Dietitians and HCP's accommodating family members and collaborating with them to provide care. As will be discussed later, *family support* was important to enabling participants' ***Resilience***.

> *[My wife] she lived with me, so she got so good; she started doing the nurse's jobs. They were going to give here a skirt and everything. Yeah, she'd change the bed before [the nurses] got there…. If you're there long enough, you get to be one of the family. And they depended on her too at times.*

Providing information. Receiving appropriate, timely, and transparent information about TF was described as comforting and helpful. For example, participants described feeling better prepared for TF when any potential ***DISCOMFORT*** associated with the therapy was explained in advance.

> *So just talk me through it or explain it to me. Like, when the young nurse put the tube feed in my nose, she's like, "Okay, this is what I'm going to do; this is how it's going to feel or how it should feel." She explained from head-to-toe, A-to-B, "This is what we're doing." Before she started, she asked if I had any questions for her. And then, as we went along, as she was putting it in, she's explaining everything to me, which made me feel way more comfortable about having the tube being put in. So she was awesome. Yeah, very informative.*

Dietitians and HCPs who were honest about the positive and negative aspects of TF were easier for participants to ***Trust*** and consequently these participants were more *tolerant* of the ***DISCOMFORT*** experienced. In contrast, when potentially helpful information about TF was not provided or was insufficient, Trust in Dietitians and HCPs was eroded and participants found being *tolerant* challenging.

> *Yeah, the nurse said, 'This is going to just…you'll feel a little bit…' But I know that…I feel that every time they start probing something in you. Always just going to be a little twing in the start, "Yeah, okay."[rolls eyes]…no, I squirmed and I hung onto that [bed rail] the whole time[makes choking sounds]…It was just a pain that is just so irritating and everything…* ***They lied*** *[emphasis].*

Emotional support. The emotional support provided by Dietitians and HCPs established a connection with participants that supported the development of ***Trust***. Emotional support was described as receiving kindness, friendliness, encouragement, and comforting, appropriate touch from Dietitians and HCPs. Participants described either receiving or not receiving forms of emotional support, ranging from "there are a couple nurses who are downright mean", to, "everyone's been really nice." Participants appreciated the benefits of developing a friendly rapport with their Dietitians and HCPs.

> *And the [specialized unit] in [Southern Ontario], the healing unit, everybody gets so close to you, that we actually are close to a few of the caregivers, and they would bring me their own food that they would make…It was like a little family. The experience was really good with the people. They helped a lot.*

A friendly relationship was developed when Dietitians and HCPs provided support that was perceived as above and beyond their regular duties as well as when Dietitians and HCPs injected humour into their care.

> *…I wanted potato chips…constantly potato chips. And I remember [Dietitian's name] saying to me, she goes, "Potato chips are good. There are a lot of calories in them, and you need to put on weight." And then she came back about half an hour later, she goes, "Did you know that a Dietitian just told you to eat potato*

> *chips?" And I, I just laughed, and she started to laugh. And…we kind of became friends.*

The provision of encouraging statements during TF was also appreciated, "The nurses called me a trooper for trying [tube feeding] out." Supportive communication at all stages of TF therapy encouraged participants' ***Resilience*** discussed later in this chapter.

When Dietitians and HCPs suggested relaxation techniques, such as deep breathing to calm anxiety or when they provided appropriate physical touch, participants felt comforted during times of distress.

> *Just even hold my hand. You know, a pat on the back…when I first had to learn how to roll over from side to side to change my dressings, the one nurse, she put her hand out to help me. And the other nurses – the meaner ones [laughs] – didn't do that, you know.*

Emotional support helped participants believe that they were important to their Dietitians and HCPs. Most participants described receiving comfort, such as appropriate physical touch from their Nurses, but added that they would appreciate this form of support from any HCP, including Dietitians.

> *…it wouldn't matter if it was a Doctor or a Dietitian [providing touch]. Whoever's caring for you at that moment that just shows that they do care. They're not just there doing that job. You know, that they actually like their job.*

Participants described feeling well cared for by the "team" of HCPs even if the Dietitian was not described as having a supportive role during TF therapy. However, for those who experienced it, additional support from Dietitians was described as helpful and comforting. This participant, in reaction to whether she would appreciate a Dietitian holding her hand, summarized the need for Dietitians to provide more comforting forms of supportive care:

> *They should. Because the Dietitian has an important role too. They've got to feed you. And if people aren't getting the food or anything good, it's not good. Because food is comfort.*

The participants in this study have demonstrated that there are many forms of *Dietitian and HCP support*, which are appreciated during TF. The support provided by Dietitians and HCPs generated in participants a better understanding of TF while increasing comfort, safety, and their sense of control. The majority of participants who described a supportive connection with their Dietitians and HCPs expressed that they could ***Trust*** them. These participants described feeling certain of the ***NECESSITY*** for TF and together with the additional ***Meaning*** ascribed to the therapy, maintained this belief throughout the experience. Alternatively, the frustration and anxiety felt by some participants generated by perceptions of inadequate support diminished their ***Trust*** in Dietitians and HCPs, leaving some participants insecure about their TF care and in some cases questioning the ***NECESSITY*** of TF while threatening any additional positive ***Meaning*** attributed to the therapy.

Resilience. ***Resilience*** is described as including participants' personality traits and the social and therapeutic influences that facilitated coping during TF therapy. Tube feeding was a challenging experience. Participants were required to draw on elements of their personality such as: *hopeful outlook*, a *sense of humour*, and *strength,* influenced by the support of families and HCPs, to enable them to cope with the therapy. Their illnesses and TF trajectory also influenced development of ***Resilience***. The categories and sub-categories relating to participants' ***Resilience*** are outlined in Figure 5.

Resilience

- *Hopeful outlook*
- *A sense of humour*
- *Strength*
- *Coping strategies*
    - *Cognitive: distancing, reframing, minimizing*
    - *Action-oriented: troubleshooting, negotiating changes, contravening care*
- *Tube feeding trajectory*
- *Family support*
    - *Being present*
    - *Being instrumental with care*
    - *Providing remote support*

Figure 5. Categories and sub-categories of the theme ***Resilience***

Hopeful outlook. Most participants described having a positive attitude with expectations of favourable health outcomes. Admitting to having a *hopeful outlook* was common among participants regardless of the stage of their illness.

> *You have to be positive in this situation. Like, where I am, being negative, you're just going to get depressed and bummed out about everything. I can't afford that; this is literally it for me. If I don't do things properly, I could have a chance at losing my left leg. And that chance is too scary to mess around with. I'll have to relearn to walk again, the Doctor said, once I get healed and I'm able to get out of the bed. And knowing the timelines, at least it's giving me a mental picture of, 'Okay, so, I see myself in the Physio Room…on those bars…helping me walk'…I picture myself doing all this stuff in order to keep myself grounded and mentally looking forward.*

Encouraging and supportive communication from Dietitians, HCPs, and family members helped participants maintain or form a *hopeful outlook* during TF therapy.

> *Is everything going to taste awful for the rest of my life, or will my body adjust? There were so many 'ifs'…and the nurses kept saying, 'John just remember it's temporary…and keep pushing through it, and just keep trying…and don't give up.'…it gave me hope.*

Sense of humour. Several participants maintained a sense of humour about their experience with TF. Following completion of TF therapy, some participants would smile or laugh while reflecting on their experiences with TF ***DISCOMFORT***. Participants who remained on TF stated they could laugh at visitor's uninformed reactions to their NGT while others could inject humour into their interactions with Dietitians and HCPs. For example, one participant was able to joke with his Physician about having steak and eggs following removal of the NGT despite knowing he was being ordered a minced-texture diet.

Many participants also described experiencing what they perceived as periodic negative emotions during TF, such as a strong desire to "run away"**,** "beat someone up", or cry, as well as "feeling depressed", and yelling angrily at the staff. For the most part, these participants described balancing their hopeful outlook with these negative emotions, "Like all of those feelings were just temporary…And I hate going there you know?" Some participants, such as those with a progressive, chronic disease, who described a number of negative emotions, did not demonstrate a *hopeful outlook*, reflecting a more pessimistic attitude about their future.

Strength. *Strength* was a trait described by a number of participants as an enabler to ***Resiliency*** because being strong was synonymous with health. Participants described mental discipline, and strength of character, when they discussed strength.

> *…I think you just have to deal with [tube feeding] and take your time and you've got to be pretty strong, I guess, to be in these kinds of situations. You have to be or else your…body will suffer along with it if your mind is not strong.*

Participants who described themselves as strong were found to rely on several different coping strategies with an emphasis on action-based coping.

Coping strategies. In addition to knowing the trajectory of the TF experience and receiving Dietitian, HCP, and family member support, participants employed a number of coping strategies that they described as enabling them to effectively cope during their TF experiences. Participants coped by using *cognitive* and *action-oriented strategies* such as *distancing, reframing, minimizing, troubleshooting, negotiating changes to, and contravening care*.

Cognitive strategies - distancing. Distancing was a temporary coping behaviour commonly described by some participants during the initial stages of TF. As described in the *knowledge of tube feeding* section of this chapter, some participants were overwhelmed with the acuity of their illness and diagnosis. Participants coped by relinquishing decision-making control to their Dietitians and HCPs thus distancing themselves from the situation. While distancing themselves, participants expressed little desire to learn about TF or to remember information about the treatment. *Distancing* enabled ***Resiliency*** during this early period of TF, described by participants as being *indifferent*, "At the time, [tube feeding] was just another thing they're putting on my body because I had all the other things, the vacuums, and intravenous tube, now a feeding tube."

Cognitive strategies – reframing. *Reframing* is the cognitive skill some participants used to view TF as something they were doing rather than as something being done to them. These participants described themselves as "being on the job" while receiving TF establishing a sense of control over their situation and a purpose, "…if anything, [tube feeding] more motivates me. I remind them, "Oh, don't forget to flush it, don't forget to clean it so it stays open."

Cognitive strategies - minimizing. Participants commonly minimized the significance of TF and their ***DISCOMFORT*** with statements such a: "…suck it up" and "It's just pain". Reframing helped many participants to be *tolerant* of TF ***DISCOMFORT*** and to express greater satisfaction with their TF experience. For some, this strategy failed with prolonged or profound ***DISCOMFORT*** while others who did not establish the ***Meaning*** of TF as beneficial could not reframe their situation. Consequently, some participants responded to TF ***DISCOMFORT*** with *resistant* behaviours.

Action-oriented strategies. To minimize the ***DISCOMFORT*** associated with TF, many participants employed *action-oriented strategies*. Some participants described feeling compelled to take action over their care because of prohibitive hospital restrictions or because of a lack of *Dietitian and HCP support*. *Action-oriented strategies* were described by participants as intervening in their care with or without the assistance of their Dietitians and HCPs and ranged from *troubleshooting* inconveniences and restrictions with the TF, to *negotiating*, or *contravening* their care. Action-oriented strategies directed at alleviating the ***DISCOMFORT*** with the TF regime allowed participants to feel that they had some control of their situation. By employing different strategies, participants could continue being *tolerant* of TF or they resisted the therapy, depending on how necessary they felt the therapy to be.

Action-oriented strategies - troubleshooting. For participants who found beneficial ***Meaning*** in TF and considered it an absolute ***NECESSITY***, action-oriented strategies were described as *troubleshooting* their TF regime. Successful *troubleshooting* enabled participants to continue with TF in a *tolerant* fashion while unsuccessful efforts created frustration that for some led to negative *resistant* behaviours. The most common form of *troubleshooting* was to manipulate the TF equipment. As discussed in the ***DISCOMFORT*** section of this chapter, the restrictions and inconveniences associated with TF were both annoying and frustrating for participants while they desired more independence with the TF equipment. Some participants, especially those in hospital for long periods, would stop the feeding pump themselves instead of waiting for a nurse in order to avoid the inconvenient beeping noise. Preventing interference with eating, irritation of the nostril containing the NGT, tube blockage, and accidental NGT removal was a priority for participants so most would adjust the NGT to mitigate this risk, "I unhook this [nasogastric tube], and I'd hook the tube around my ear. If I don't I'm always sticking my fork into it…And that way, I get a clear passage for the mouth [laughs].

When troubleshooting problems with the TF failed to be effective and the ***NECESSITY*** for TF was or became dubious in the presence of substantial ***DISCOMFORT***, participants were *resistant* to the therapy, often leading to interruptions in their TF regime or the discontinuation of the therapy. *Resistant* behaviours were defined by any action taken to oppose TF amidst the ***DISCOMFORT*** of the therapy and included positive behaviours such as negotiating changes to the TF regime or physically intervening with TF care, a negative response that often ended the therapy prematurely.

Action-oriented strategies – negotiating changes. Given participants' desires to alleviate ***Discomfort***, some looked for alternatives to the prescribed TF regime by negotiating changes with their Dietitians and HCPs. Participants commonly requested a different TF formula and changes to the delivery schedule or to the volume of TF delivered. Negotiating change was either effective or ineffective depending on the allowances of the participant's illness and the type and degree of *Dietitian and HCP support*, such as shared-decision making behaviours.

> *…Because they were crushing my pills and putting them in the nose [tube]. And then I could start tasting [the tube feeding formula] at the top of the mouth, or around the neck. And then I started to taste the pills and all that stuff. So, I said, "Don't fill me up too much." And so they had to start doing tube feeding in stages. You know, wait a half an hour, come back, do a little bit more.*

Action-oriented strategies – contravening care. If participants were unable to troubleshoot or negotiate changes to their TF regime, participants became opposed to the therapy, *contravening care* in an effort to eliminate the ***DISCOMFORT***. For example, one participant would accidently pull out his NGT every night when being abruptly awoken by the hospital's paging system. The participant, with the help of his wife, was able to partially manage this problem with the addition of a clock radio at bedside to add "white noise" while also taping a "Depends" over the intercom to muffle the noise. The participant added that some Nurses were supportive of his techniques while others would remove the "Depends" every shift. When this strategy failed to work over time, the frustration and pain with multiple NGT reinsertions led the participant to pull his NGT in defiance of the therapy, "The main disadvantage of TF is that is was me, I was sore….yeah, I yanked [the nasogastric tube] out. I told [the nurse] I didn't want it anymore. It was very painful."

When resistant behaviours led to interruptions to the TF regime or the discontinuation of the therapy participants were pleased that their ***DISCOMFORT*** was abated. For those participants who ascribed beneficial ***Meaning*** to TF, frustration and worry about their nutritional status once again took precedence, "[I was] a little bit disappointed because I was hoping [tube feeding] would work. Disappointing, and I'm going, 'Nothing's going to work here.' It almost defeated me." Participants looked for alternative forms of nutrition such as a calorically dense oral diet or intravenous nutrition support (TPN) if remaining NPO. Other participants agreed to resume the previously prescribed TF regime or a modified version of it. If the Discomfort was minimal and beneficial outcomes were attained, the value of TF was restored for these participants whereas others remained frustrated and *resistant* to the therapy.

Trajectory of tube feeding. The length of time anticipated for TF therapy, based on the trajectory of participants' illnesses and response to the therapy, impacted their ability to cope with the therapy. As outlined in the *Knowledge of tube feeding* section of this chapter, participants wanted to know how long TF was going to be required.

> *I just didn't know how long I was going to be on it. That's what I was worried about. I said, "I hope…I don't want to be on this for five, six, seven months." That's all I was worried about, really. But, I know it's just temporary, so…I can deal with it.*

Many participants found comfort in the knowledge that TF was an impermanent therapy, enabling them to be *tolerant* during times of ***DISCOMFORT***. When the trajectory of TF was unclear, participants expressed some frustration, "The duration of how long this is all taking is a bit of a thing…it's just getting drawn out." When the trajectory of TF was known to be required for a longer period, beyond acute care, participants who were NPO found it challenging to accept the therapy because it was incongruent with their goals, "How am I going to handle [tube feeding]? I have no idea anymore. It's nothing but a problem…When I leave here I can't lead a normal life anymore."

The existence or absence of specific personality traits, *coping strategies* employed, the *trajectory of TF*, and *family support* contributed to each participant's **Resilience** response to the difficult therapy of TF.

Family support. *Family support* was described as a resource for strength to draw on while receiving TF. There was a deep appreciation for spousal partnerships and the family bond in helping participants to get through TF. When describing the support of family members, a participant's eyes would light up. If a family member were a part of the interview, most participants would reach for their hand and smile or begin to cry. For participants with supportive family members, they all described *family support* as "fantastic". *Family support* was described by the sub-categories as *being present* and *instrumental with care*, as well as *providing remote support*.

Family support – being present. Participants described the consistent, reliable presence of family as comforting, "Even if I wasn't able to talk and just wanted to sleep, [my family] were just here for emotional support.*"* When present, family members listened, were empathetic, and provided physical and emotional comfort, "Well, I would get upset, and then I'd get upset over it, and [my family] would just try to calm me down, bring me down a level."

Family support – being instrumental with care. Family members, especially spouses, were instrumental in providing care such as assisting the nursing staff, and completing daily living tasks for participants.

> *Being here, if there's anything that I want or need, or to wash my laundry, or just come and hang out. Even if I wasn't able to talk and just wanted to sleep, [my family] were just here for emotional support.*

Family members were instrumental in helping participants cope with the ***DISCOMFORT*** associated with eating and drinking challenges. Family members supported participants by repeatedly bringing in a variety of food items from home for those who could tolerate oral intake, or as well as abstaining from consuming food or beverages in front of the participants who were NPO.

> *When [my family] were coming up to visit me, they wouldn't even bring coffee up for themselves anymore because I wasn't able to drink anything. I would never have asked them to do that, but they did. Because, it was hard, but I wasn't going to tell them they couldn't drink when they were here.*

Given the frustration and anger experienced by participants who struggled with resumption of eating and drinking, the support of family members during this challenging time was described as providing them with renewed "hope".

Family support- providing remote support. Participants appreciated remote forms of support such as regular phone calls, texts, and greeting cards from family members and friends, as well as knowing that extended family members and friends were kept informed of their recovery.

> *Our kids phone, put notes in the newspaper, put cards up around town. Never seen so many cards with our names on it. But they really support us, what we're doing…and our health.*

The various forms of *family support* provided throughout TF therapy was an essential factor in enabling participants to be resilient.

Resilience was important to helping participants tolerate TF. The presence of specific personality traits enabled participants to draw on various *coping strategies* that were effective or ineffective in dealing with the ***DISCOMFORT*** of TF. Additionally, external supports from Dietitians, HCPs and family members and the trajectory of participants' therapy affected their responses to TF, including whether TF continued, was adjusted, or discontinued.

Summary

Participants' experiences with TF in acute care were constructed from a variety of influencing factors that determined whether they considered the therapy to have been beneficial for their condition and ultimately a satisfactory experience. Tube feeding was often overwhelming because of the multiple discomforts associated with its delivery and deemed an unlikeable therapy that was challenging for participants to accept. The "evil" of TF therapy was for some participants tempered by the perception that TF was an absolute ***NECESSITY*** for their illness, whereas for others the ***NECESSITY*** was dubious.

Participants varied in their beliefs about the value of TF for their individual situations. For some, tube feeding was never or was not always considered a necessary evil during the therapeutic period. The establishment and maintenance of the ***Meaning*** of TF in addition to ***NECESSITY*** was based on participants' individual beliefs about nutrition and the efficacy of TF in relation to their goals for the illness as well as on the ***Trust*** participants had in their Dietitians and HCPs. The different levels of *Dietitian and HCP support* either reinforced participants confidence in them, building ***Trust*** or diminishing it. With precarious ***Trust*** in their Dietitians and HCPs and insufferable ***DISCOMFORT***, some participants struggled to see the ***NECESSITY*** of TF or to establish and maintain any preexisting beliefs that TF would be beneficial to their recovery.

The ***DISCOMFORT*** that inevitably resulted from TF required ***Resilience*** on the part of participants. The knowledge of the therapeutic trajectory and the existence of different personality traits, Dietitian, HCP, and *family support* allowed participants to draw on cognitive and action-based coping strategies to manage TF. A number of participants effectively managed TF ***DISCOMFORT*** enabling their ongoing tolerance. Participants who doubted the ***NECESSITY*** of TF were more likely to cope by interfering with the delivery of TF. *Contravening care* often led to the cessation of TF therapy and alternative sources of nutrition or a modified TF regime.

The relationship between participants' beliefs about the ***NECESSITY*** of TF with the degree of ***DISCOMFORT*** experienced, constructed four common responses to their experiences. When ***DISCOMFORT*** was minimal participants reacted to the experience of receiving TF with indifference or with relief. When *indifferent*, participants were commonly under significant stress in the early stages of their illness, demonstrating little interest in learning about TF and establishing the ***NECESSITY*** of the therapy or assigning additional ***Meaning*** to TF for their recovery. *Relieved* participants had sufficient *Knowledge of TF*, considering it a ***NECESSITY*** for recovery while interpreting the ***Meaning*** of TF as beneficial to attaining their goals. Participants commonly moved from being *indifferent* to *relieved* as the therapy progressed.

When ***DISCOMFORT*** was high participants reacted by being *tolerant* or *resistant* to TF. Participants who came to view TF as a ***NECESSITY*** moved from being *indifferent* or *relieved* to being *tolerant* of the therapy. These same participants could become *resistant* to TF during particular instances of profound ***Discomfort*** than return to being *tolerant* of the therapy depending on the influences of the ***Meaning*** ascribed to TF, ***Trust*** in their Dietitians and HCPs, and his/her personal ***Resilience***. Often participants who did not view TF as a ***NECESSITY*** moved from being *indifferent* to being *resistant*, interfering with care to significantly change their TF regime or stop it entirely as a means to end their ***DISCOMFORT*** and find a more meaningful source of nourishment.

The dichotomous relationship between TF ***NECESSITY*** and ***DISCOMFORT*** in relation to the various influences of ***Meaning***, ***Trust***, and ***Resilience*** created for participants an experience with TF that they defined as being a questionably necessary evil. With the value of an aversive therapy questioned, some participants had a negative experience with TF in acute care, often displaying indifferent and resistant behaviours. However, most participants were able to tolerate TF and were generally relieved that they received it; expressing gratitude for the therapy and for the care they received. Being a necessary evil, these participants were more satisfied with their TF experience as they believed it had truly benefited their recovery.

CHAPTER 5

DISCUSSION

Tube feeding is well known to be a challenging therapy to endure in the treatment or prevention of nutritional disorders during illness. Despite the potential benefits of this therapy, TF has been perceived as a questionable therapy among different patient populations, although why participants felt this way and what their responses were to the TF experience, have not always been made clear (Barbosa & Freitas, 2005; Kwong et al., 2014). This is the first study in the English language to provide a rich description of the complex, inter-related factors that influence the patient's perception of the ***NECESSITY*** of this therapy in acute care, influencing their satisfaction with the TF experience, and informing the patient-centered practices of Dietitians and HCPs.

In this chapter will be highlighted the new knowledge added to the body of literature about the patient's experience with TF in acute care. The findings overall will be compared and contrasted with the existing TF literature, including a sample of the literature examining patients receiving TF as an outpatient while living at home, since the acute care literature about the TF experience is limited. A discussion of the contextual findings of this study in relation to the literature about TF will be presented first. This will be followed by a synopsis of the new knowledge arising from the current findings, and a discussion of how the interpretation of the experience as ***A NECESSARY EVIL?*** relates to what has been reported about TF to date. Study limitations and recommendations for teaching, practice, and research based on the findings conclude this chapter.

A NECESSARY EVIL? New Knowledge

Several findings in the current study contribute new knowledge to the phenomenon of the patient's experience with TF in acute care. The following is a synopsis of the new findings that will be explicated more fully, where appropriate, throughout this chapter.

- The perspective of Canadian, acutely ill participants receiving TF with an impermanent intent.
- The influence of the North Western Ontario context within small-to-moderate sized, acute care hospitals caring for participants on TF.
- The rich description of the complex, inter-related themes that influenced the patient's experience with TF in acute care.
- The varying participant perceptions of TF ***NECESSITY*** culminating as ***A NECESSARY EVIL?***
- Participants' common responses to TF therapy and the factors influencing them.
- The metabolic abnormalities associated with TF contributing to participant ***DISCOMFORT***.
- The influence of hospital policies that exacerbated the *inconveniences* and *restrictions* associated with TF.
- Participants' desperation to prevent accidental NGT dislodgement.
- The fear of death from starvation among the acutely ill for whom TF has an impermanent intent.

- Apathy among participants with regards to the provision of information about TF during stressful periods.
- The lack of ***Meaning*** TF has among those at lower nutritional risk.
- The connection between ***Trust*** and *Dietitian and HCP support* and how this influences participant perception of TF ***NECESSITY*** and ***DISCOMFORT***.
- The importance of providing adequate inter-and intra-professional care in an inpatient setting to enhance participants' Trust in Dietitians and HCPs.
- The importance of providing adequate and timely information about TF to assist participants with ascribing ***Meaning*** to TF and enhancing ***Trust***.
- Detailed descriptions of Dietitians' (un) supportive practices with TF in acute care.
- The need for Dietitians and HCPs to provide better *emotional support*, including appropriate, physical touch.
- Personality characteristics among tube fed participants in acute care that enabled ***Resilience***.
- Coping strategies employed by acutely ill participants on TF.
- The supportive practices of family members caring for participants on TF in acute care.

A NECESSARY EVIL?: **The Context**

The sample for the current study included participants receiving TF in acute care and is the first to include Canadian participants. The sample for the one parallel study found, involved Portuguese acute care patients receiving TF (Barbosa & Freitas, 2005). A second similar study, involved critically ill Swedish participants receiving TF (Persenius et al., 2009). The similarities in findings across the different cultural groups speaks to the possibility that TF may be experienced similarly by participants regardless of their cultural influence and geographical location. The differences noted in participant experiences, addressed later, may well be secondary to other contextual differences including culture, important for Dietitians and HCPs to appreciate when developing new approaches to caring for this patient population.

Acute illness is associated with uncertainty, stress, and anxiety, which had an impact on participants' perception of the ***NECESSITY*** for the therapy. Similarly Barbosa and Freitas (2005) participants considered TF to be a form of life support and an urgent requirement of their illness, an opinion that for some changed as the therapy continued as it did for the participants in the current study. Additionally, Taylor (1979) found that being hospitalized reduced a patient's sense of autonomy and control over their body and environment, a finding of the current study. Participants in the current study required different coping strategies than did participants living at home with TF and receiving outpatient-care (Meyer-Chilton et al., 2011).

No other Canadian studies have yet been reported examining the patients' experiences with impermanent TF in acute care, and none have been reported in which the sample was from average to smaller sized acute care hospitals in smaller municipalities. Up to this point, Canadian TF research that has been published has been conducted in larger metropolitan areas (Kwong et al., 2014; Osborne et al., 2012; Van Rosendaal & Verhoef, 1999; Verhoef & Van Rosendaal, 2001). In contrast to the ICU participants receiving TF in the study by Persenius et al. (2009) who reported excellent support from HCP's, the participants in the current study reported variable Dietitian and

HCP support on the medical and surgical wards. This may be a result of the different practice realities on the hospital ward compared to the ICU. On the wards, Dietitians and HCPs are generalists, working with patients with multiple diseases, uncertain TF trajectories and clinical outcomes amidst larger patient caseloads and often undefined interprofessional teams. Thus the practice reality on general medical and surgical wards in smaller hospitals in Canada is fraught with challenges that may impact Dietitians and HCPs ability to provide supportive patient-centered practices.

A NECESSARY EVIL? The Patient's Experience

No other literature was found wherein the patients' experiences with TF in acute care was interpreted to be ***A Necessary Evil?*** .This central theme, presented as a question, reflects not only the emotional conflict experienced by acutely ill participants who endured a highly uncomfortable therapy but also the variation in the acceptance of this therapy. The challenges associated with TF leading to a dislike for the therapy have been well described (Barbosa & Freitas, 2005; Brotherton et al., 2006; Jordan et al., 2006; Kwong et al., 2014; Merrick & Farrell, 2012; Meyer-Chilton et al., 2011; Osborne et al., 2012; Walker, 2005). However few studies published in the English language, examining participants receiving TF with an impermanent intent, have reported both on participants' varying perceptions of the ***NECESSITY*** for this therapy and the rationale provided by those who considered TF unnecessary (Barbosa & Freitas, 2005; Osborne et al., 2012). The findings of the current study add new knowledge within the English language literature about the rationale for participants' varying perceptions of the ***NECESSITY*** for TF, as well as their responses to the therapy, contributing to a richer understanding of the patients' experience and what Dietitians and HCPs can do to make a difference.

Interestingly, the phrase “A Necessary Evil?” was found to be a central theme in a study examining nurses' perceptions of the use of physical restraints in a mental health setting (Perkins, Prosser, Riley, & Whittington, 2012). In a similar vein, the participants in the current study perceived TF to either be their best option given their illness situation, or not, concluding that the therapy was ***A NECESSARY EVIL?***

DISCOMFORT

Findings associated with the physical discomforts of TF experienced by participants in the current study, supports the literature on TF in acute care (Barbosa & Freitas, 2005; Bruning et al., 1988; Padilla et al., 1979; Persenius et al., 2009). However, that metabolic abnormalities developed which required frequent insulin administration was a new finding unreported in the extant literature. See Figure 6 for the categories within the major theme ***DISCOMFORT***.

A NECESSARY EVIL?: DISCOMFORT

Physical discomfort
Restrictive discomfort
The discomfort of inconvenience and fear
The discomfort of eating and drinking challenges

Figure 6. Categories of the major theme ***DISCOMFORT***

The inconveniences and restrictions associated with feeding tubes and feeding equipment whether patients are in hospital or living at home have been addressed in the literature (Brotherton et al., 2006; Jordan et al., 2006; Padilla et al., 1979; Rickman, 1998; Roberge et al., 2000). The current study highlights that these TF inconveniences and restrictions are compounded by the institutional care policies that further reduced participants' sense of autonomy and control and increased their frustration.

Barbosa and Freitas (2005) found that acutely ill Portuguese participants on TF were fearful of TF, i.e. the tube, the therapy, and the discomforts experienced because they viewed TF as abnormal, which consequently had a negative impact to their self-image and self-esteem. These findings are not supported by the findings of the current study where participants expressed acceptance of TF as a familiar medical therapy. The differences between these findings may be explained by the Social Representation framework informing the study by Barbosa and Freitas (2005).

Findings from the current study highlight that the stress, fear, anxiety, and guilt associated with the prevention of, and accidental NGT dislodgement, was especially distressing for participants, a finding not previously noted in the existing TF literature. Alternative nutritional therapies could be explored and discussed with patients prior to repeated reinsertions. This practice may be beneficial in both reducing patients' anxiety with nutritional concerns and enhancing their physical comfort, a recommendation supported by authors studying critically ill patients' on TF (Persenius et al., 2009).

Fear of death from starvation was a finding of the current study, unreported to date in the existing literature related to acutely or critically ill patients on TF with an impermanent intent. However, this was a fear reported by Van Rosendaal and Verhoef (1999) among Canadian hospitalized participants as a factor in their decision to have a PEG placed for long-term use following discharge. Van Rosendaal and Verhoef (1999) noted that death from starvation is abhorrent in Canadian culture, a concept supported by the findings from the current study and found to be the impetus for some participants agreeing to, or continuing with, TF. Participants descriptions of a desperate desire for water while NPO is consistent with findings reported in the extant literature about TF (Padilla et al., 1979; Persenius et al., 2009) and highlights the need to ardently address and alleviate this ***DISCOMFORT*** whenever possible.

Participants in the current study experienced challenges associated with resumption of eating and drinking that included a dependence on TF because of the sensory changes that served as a barrier to adequate oral intake. This created feelings of frustration and fear, findings that are consistent with the findings from other TF studies with an acutely and critically ill patient sample (Barbosa & Freitas, 2005; Persenius et al., 2009). Sensory changes impeding adequate oral intake have been well described for the head and neck cancer patient population (Bernhardson, Tishelman, & Rutqvist, 2007; Bruning et al., 1988; Kwong et al., 2014; Osborne et al., 2012). This finding was highlighted in the current study as a challenge for participants with a range of clinical disorders, especially if hospitalized for an extended period on TF. The findings of the current study support those of Barbosa and Freitas (2005) and Persenius et al. (2009) who noted that for acutely and critically ill participants on TF, the return of volitional oral intake marked the end of the need for a medical form of nutrition and the return of their independence and control. With the return of their autonomy, participants had hope for goal attainment.

NECESSITY **and** ***Meaning***

For those who considered TF to be a necessary evil, the discomforts associated with this therapy were balanced by the potential for improved health outcomes. Participants in both the inpatient and outpatient TF literature have described the

NECESSITY for TF as a clinical need because of the demands of their illness (Barbosa & Freitas, 2005; Kwong et al., 2014; Osborne et al., 2012; Persenius et al., 2009). The current study is the first to describe participants' perception of the ***NECESSITY*** of TF as a continuum, resulting from participants' ability to be ***Resilient*** with the varying degrees of ***DISCOMFORT*** experienced, the ***Meaning*** attributed to TF, and the ***Trust*** placed in their Dietitians and HCPs. See Figure 7 for the major theme ***NECESSITY*** and the categories and sub-categories within the theme ***Meaning***.

A NECESSARY EVIL?: NECESSITY and Meaning

- *Personal goals*
- *Perceived efficacy*
  - *Belief in the value of nutrition*
  - *Knowledge of TF*

Figure 7. The major theme ***NECESSITY*** and the category and sub-categories of the theme ***Meaning***

Participants in the current study looked for the ***Meaning*** of TF in relation to their goals to both motivate their engagement with this therapy and to engender hope for recovery, a finding noted in the acutely and critically ill populations on TF (Barbosa & Freitas, 2005; Persenius et al., 2009). Participants in the current study found ***Meaning*** in TF if they considered adequate nutrition valuable during illness and perceived TF to be efficacious in relation to their personal goals. Thus they both required and expressed a desire for knowledge about TF to understand and evaluate the potential efficacy of the therapy, a finding also noted in the broader TF literature (Barbosa & Freitas, 2005; Van Rosendaal & Verhoef, 1999). A new finding from the current study was that acutely ill participants, when under substantial stress, are seldom receptive to TF information, but their desire for comprehensive but brief written or verbal information, changed as their condition improved. This finding underscores the importance of Dietitians and HCPs regularly inquiring with patients as to their information needs throughout the therapy, while considering different ways to effectively communicate this information, a recommendation noted in the ICU literature on TF (Persenius et al., 2009).

Nutrition was highly valued among participants in the current study as essential for health, supporting the findings of others studying Canadian patients on TF (Van Rosendaal & Verhoef, 1999). Further, the findings of the current study support the work of those examining both the acutely ill and outpatient populations on TF who found that many expressed profound relief that they were being nourished by TF (Barbosa & Freitas, 2005; Kwong et al., 2014; Osborne et al., 2012; Verhoef & Van Rosendaal, 2001). Improved outcomes such as increased strength, energy, and wound healing during the therapy, while upon completion, attributing TF to their survival, were key benefits cited by participants.

Similar to the findings by Osborne et al. (2012), some participants in the current study considered TF unnecessary. However, the current study added participants' rationale for this perception: participants at low nutritional risk or who were terminally ill, found little ***Meaning*** in TF, expressing that an aggressive nutrition support regime with a continuous high caloric load, was unwarranted during their illnesses and in many respects was a barrier to their goals, such as weight loss, comfort, or achieving normalcy in their activities of daily living. This finding is supported by the literature on terminally ill patients receiving TF (Verhoef & Van Rosendaal, 2001). However, the finding related to participants at low nutritional risk has not previously been reported, although Barbosa and Freitas (2005) found that as their participants' health improved, the participants perceived TF as being unnecessary as they felt it was no longer required for their condition. Between the time of the first and second interviews, the healthier participants in the current study reported that they recovered to normal or near-normal function following TF therapy, while those who were terminally ill, had passed away during this period. These findings support Verhoef and Van Rosendaal (2001) questions as to the value of an aggressive nutrition support regime in patients for whom there may be little nutritional benefit or improvements to their quality of life. Interestingly, among those who found beneficial ***Meaning*** in TF initially, they also described it as efficacious at the completion of the therapy despite caloric goals never being achieved, a finding also noted among the critically ill population on TF (Persenius et al., 2009). This may reflect a belief that lower energy intakes are sufficient during a brief illness or that some participants had inadequate knowledge about TF, questions that require further research.

These findings reflect the importance of working with patients to understand their beliefs and goals with respect to nutrition during illness so as to understand the ***Meaning*** they ascribe to different nutritional therapies. Dietitians and HCPs need to ensure participants understand all aspects of the therapies being offered, and need to develop a mutually acceptable nutritional care plan, recommendations previously suggested by authors studying participants on TF (Peteet, Medeiros, Slavin, & Walsh-Burke, 1981; Van Rosendaal & Verhoef, 1999; Verhoef & Van Rosendaal, 2001).

Trust

With ***Trust***, participants in the current study, like their critically ill counterparts (Persenius et al., 2009), were comforted and relieved that they were receiving TF. ***DISCOMFORT*** could be better tolerated because participants were confident in their Dietitians' and HCPs' decisions to continue with TF therapy, believing that their concerns would be addressed. Patient acceptance and satisfaction with TF has been noted when patient-centered care is provided among outpatient TF populations (Kwong et al., 2014). Current findings support that ***Trust*** in Dietitians and HCPs was variable and when supportive practices were absent, participants failed to see the ***NECESSITY*** of TF, leading to resistant behaviours and a more negative experience, outcomes also noted among other acutely ill populations on TF, but not discussed as being linked to *Dietitian and HCP support* (Barbosa & Freitas, 2005). See Figure 8 for the categories and sub-categories of the theme ***Trust***.

A NECESSARY EVIL?: Trust

- *Prescriptive care*
- *Dietitian and health care provider support*
    - *Being instrumental*
    - *Providing information*
    - *Being collaborative*
    - *Providing emotional support*

Figure 8. Categories and sub-categories of the theme ***Trust***

Supporting Persenius et al.'s (2009) findings with critically ill TF patients, the participants in the current study preferred both a prescriptive approach to care, reflecting inherent ***Trust*** in their Dietitians and HCPs, as well as a *collaborative support* approach to care, including participation in shared-decision making practices, that over time built or maintained ***Trust***. The patient-centered concepts of *instrumental*, *informational*, *collaborative*, and *emotional, Dietitian and HCP support* described as essential by participants in the current study, were foundational to the development of ***Trust*** in their HCPs, which in turn was fundamental to shaping their perception of the ***NECESSITY*** of TF, their tolerance to ***DISCOMFORT***, and their satisfaction with the experience. The concept of participant ***Trust*** in Dietitians and HCPs as having an influence on the perception of TF ***DISCOMFORT*** or ***NECESSITY*** has not been explored in the TF literature, although in the study by Kwong et al. (2014) they did note that their outpatient participants appeared to put ***Trust*** in their healthcare team.

The findings of the current study support those by Persenius et al. (2009) that both acutely and critically ill participants on TF appreciate the *instrumental support* provided by HCPs. Persenius et al. (2009) noted that *instrumental support* increased feelings of safety among ICU participants on TF whereas in the current study, participants described feeling more comfortable and less anxious. The importance of Dietitians and HCPs working as part of inter- and intra-professional care teams to increase ***Trust*** was a unique finding compared to the acute patient literature on TF. The variability in current study findings support those in the outpatient TF literature that the lack of interprofessional care creates frustration among participants but enhances a feeling of support when such a team is available (Brotherton et al., 2006; Jordan et al., 2006; Kwong et al., 2014; Mayre-Chilton et al., 2011; Osborne et al., 2012; Rickman, 1998).

Informational support was the most commonly noted form of healthcare provider support desired by participants in the current study and by those in an outpatient setting

(Brotherton et al., 2006; Jordan et al., 2006; Kwong et al., 2014; Van Rosendaal & Verhoef, 1999). Desired *informational support* included verbal or written information covering what TF is, how it works, and how long it will be required. The current study findings supports those among outpatient participants from Brotherton et al. (2006) and Jordan et al. (2006) that the provision of adequate information was perceived as variable which may have contributed to participants' negative satisfaction with TF. However, the current findings add that when adequately informed, participants were able to ascribe ***Meaning*** to the therapy and felt comforted by and confident in their TF regime and care providers. Additionally, providing comprehensive and straightforward information about the NGT insertion procedure, balanced with comforting strategies, built ***Trust*** and enabled participants in the current study to better endure the procedure, findings that are consistent with the literature on effective NGT insertion techniques (Penrod, Morse, & Wilson, 1999).

This study is the first in the literature on TF to provide tube fed participants' detailed descriptions of their Dietitian's supportive practices and his or her role in the their TF experience. Dietitians were described by the current sample as being synonymous with food and nutrition and may explain in part why participants' perceptions of the Dietitians role varied. Tube feeding was not viewed as food, but as a medical therapy, a common finding in the TF literature (Brotherton et al., 2006; Walker, 2005). In the early stages of TF therapy, participants perceived that TF was prescribed by Physicians and managed by Nurses, rather than by Dietitians. In the current study, food and oral intake was representative of the recovery stage of participants' illnesses with which Dietitians were perceived as having an important role.

The absence of known Dietitian support did not seem to impact participants' experiences with TF. However Dietitians who were described as being actively involved in TF care had clearly developed relationships with participants that were described as both supportive and unsupportive. In the present study, the experience with TF was negative when the Dietitian's prescriptive approach was incongruent with participants' desires for *collaborative support* described as shared-decision making, findings that are reflective of the findings of Hancock et al. (2012) who examined non-tube fed patients' experiences of Dietetic consultations. Frustrated participants looked to other HCPs to assist with diminishing their ***DISCOMFORT*** and to find alternative nutritional therapies in the current study. On the other hand, Dietitians seemed to enhance the participants' more positive experiences when they adopted a patient-centered approach, also supporting the findings of Hancock et al. (2012). In the current study, Dietitians were considered supportive when they were attentive and responsive to TF concerns and oral diet changes, as well as when they respected participants' values and beliefs about nutrition during illness, while simultaneously imbuing humour and friendliness into their interactions.

Dietitians and HCPs who provided *emotional support* during TF, in the form of empathy, kindness, friendliness, and appropriate physical touch, such as hand-holding or a back-rub had not previously been described in the extant literature on TF. Emotional support in the clinical environment demonstrated care provider concern and assisted with establishing a connection with patients, increasing ***Trust*** and leading to a more effective therapeutic relationship (Vandall-Walker, 2002/8). Participants in the current study described variable emotional support from their Nurses and Dietitians while adding that this form of support would be desired from any care provider.

Given that Dietitians were perceived as connected with food and nutrition, participants expressed a desire for *emotional support* from their Dietitian to ease TF discomforts amidst the absence of normal food and beverage intake. The concept of Dietitians providing comforting and appropriate physical touch to patients has not previously been described in the TF or Dietetics literature and requires further study to determine Dietitians' readiness to engage in this form of support. Additionally, the impact of Dietitians and HCPs providing more *emotional support* on participant satisfaction with TF could be evaluated for effectiveness in improving the therapeutic relationship and satisfaction with outcomes.

The variation in Dietitians' patient-centered care practices reported among participants may be due in part to the different experiences and abilities of Dietitians, as well as the environment where they work. These findings are consistent with the patient-centered care and Dietetics literature, that Dietitians are unsure how to address participants emotional concerns during consultations and are hesitant to recognize the patient's expertise and authority in the working relationship (MacLellan & Berenbaum, 2006, 2007). Furthermore, Dietitians have reported confronting barriers such as lack of time or organizational restraints that impede their ability to develop effective therapeutic relationships with patients (MacLellan & Berenbaum, 2006). Additionally, Dietitians have identified barriers to adopting shared decision-making practices such as perceived lack of interprofessional support, patient characteristics, and prohibitive clinical conditions (Desroches, Lapointe, Deschenes, Gagnon, & Legare, 2011). These findings seem to be consistent with the practice realities on the general medical and surgical wards in the hospital setting. However there may be cultural characteristics of the hospitals, wards, and team dynamics of the current study context that were unique and thus this question requires investigation in a different location.

Results from the current study indicated that some in-patient Dietitians were overcoming barriers to patient-centered care and were making a positive impact on their patients' experiences with TF. The supportive practices described by the tube fed participants in this study may serve as a catalyst for Dietitians to improve their patient-centered practices with this patient population. In guiding Dietitians towards improved patient-centred care, the recently developed “Collaborative, client-centred, nutrition education framework and practice points (3CNE)”, may have benefit. This new framework, developed by Canadian Dietetic educators/researchers, and published this month, is the first to guide Dietetic students and practicing Dietitians towards considering the specific needs and preferences of patients (clients) and how these might change with different times, places, or health status (Morley, MacLellan, Traviss, & Cividin, 2016). Thus, the 3CNE could be applied in educational settings as a framework for developing flexible approaches to patient-centred care with hospitalized patients on TF, while also examined for applicability and effectiveness among the Dietitian group caring for this patient population.

Resilience

The current study supports the work of other researchers who found that tube fed patients are resilient in the face of TF ***DISCOMFORT*** (Kwong et al., 2014; Merrick & Farrell, 2012; Persenius et al., 2009; Thompson, Durrant, Barusch, & Olson, 2006).

Participants in the current study commonly described being angry, anxious, and frustrated with TF, negative emotions that had been described previously by patients receiving TF in the ICU and outpatient settings (Brotherton & Abbott, 2009; Jordan et al., 2006; Merrick & Farrell, 2012; Persenius et al., 2009; Walker, 2005). The current study extended this knowledge to include personality characteristics of the participant sample, the common coping strategies employed in response to the TF experience in acute care, and the factors that enabled coping. Figure 9 outlines the categories and sub-categories of the theme ***Resilience***.

A NECESSARY EVIL?: Resilience

- *Hopeful outlook*
- *A sense of humour*
- *Strength*
- *Coping strategies*
    - *Cognitive: distancing, reframing, minimizing*
    - *Action-oriented: troubleshooting, negotiating changes, contravening care*
- *Tube feeding trajectory*
- *Family support*
    - *Being present*
    - *Being instrumental with care*
    - *Providing remote support*

Figure 9. Categories and sub-categories of the theme ***Resilience***

Regardless of their perception of the ***NECESSITY*** of TF, participants described themselves as having *strength* with a *hopeful outlook* and a *sense of humour*, characteristics that for some, helped them to overcome the negative emotions associated with TF. These personality characteristics were especially helpful among participants who valued TF and who then engaged in positive coping strategies to ensure tolerance in an effort to maximize beneficial outcomes, a finding noted in the outpatient TF literature

(Merrick & Farrell, 2012; Meyer-Chilton et al., 2011; Thompson et al., 2006). This study is the first to report the use of cognitive and action-oriented coping strategies among participants on TF in acute care. Thompson et al. (2006) found their participants living at home on TF also used positive cognitive and action-oriented strategies similar to *minimizing*, *reframing,* and *troubleshooting* the TF regime or equipment. These strategies may be dependent on characteristics pertaining to participants' personality and/or illness (Livneh, 2000) and highlight that coping strategies in the inpatient TF patient population require further research.

In the current study, additional action-oriented strategies such as *negotiating changes* to the TF regime by participating in decisions were found to be effective for some participants and were suggested by Peteet et al. (1981) as strategies to be encouraged. Acutely ill Portuguese participants on TF were noted to rely on religion as an enabler to coping (Barbosa & Freitas, 2005), a phenomenon not mentioned by participants in the current study that may reflect cultural, sample, or data collection differences.

The knowledge that TF was a temporary therapy for most participants influenced ***Resilience*** and supports the findings from the TF literature about participants being treated with a curative intent (Barbosa & Freitas, 2005; Kwong et al., 2014; Merrick & Farrell, 2012; Osborne et al., 2012). For participants with a longer-term or unknown *TF trajectory*, the therapy was more challenging to endure and accept, reflecting the findings of literature on patients living with TF at home (Brotherton et al., 2006; Verhoef & Van Rosendaal, 2001; Walker, 2005).

The early stage of TF therapy was described by participants as highly stressful, with many *distancing* themselves as a form of coping, a finding not previously described in the TF literature, but noted as a strategy used among the acutely ill in general (Morse & Johnson, 1991). It is important for Dietitians and HCPs to acknowledge that in the initial stage of the illness experience, some tube fed participants find little ***Meaning*** in TF, remaining indifferent to the therapy, and are commonly not open to information support. Providing written or verbal information to participants' family members at this stage may be helpful, as is the acknowledgement that information needs to be repeated across the different stages of illness.

The support of family members was found to be instrumental to promoting participant ***Resilience*** during TF, especially when oral intake was resumed, a finding supported by the TF literature on acutely and critically ill patients (Barbosa & Freitas, 2005; Persenius et al., 2009). The current study is the first to report on the specific types of support provided by family members including *being present*, *being instrumental with care*, and *providing remote support*. Dietitians and HCPs may benefit from regularly including family members in their approach to educating and supporting patients.

Contravening care by resisting TF was a coping strategy demonstrated in response to profound ***DISCOMFORT*** that resulted in interruptions to, or a premature end to, the therapy. Participants in the current study who demonstrated *resistant* behaviours found little ***Meaning*** in TF while for others any existing ***Meaning*** was threatened when the clinical need for the therapy seemed diminished by the ***DISCOMFORT*** experienced. These findings are consistent with those of Barbosa and Freitas (2005) and Persenius et al. (2009) who found that their acutely and critically ill participants on TF became stressed when the ***Meaning*** of a therapy was lost and they used different strategies to avoid ***DISCOMFORT***. Indeed, findings from the current study highlight that resuming TF in a patient who finds little ***Meaning*** in the therapy will likely exacerbate an already negative experience, whereas finding an alternative nutritional therapy may be helpful.

Limitations

A limitation of the current study was the initial use of the term “short-term” TF to describe the intended sample of participants required to answer the research question. The definitions for “short-term” and “long-term” TF arose from the practice literature on TF and are provided in Chapter One. These definitions based on a cut-off point of 30 days - shorter or longer - were initially used to differentiate between those participants who were receiving TF at home and those who were receiving TF in hospital with an impermanent intent. Thus when developing the inclusion criteria, participants who were on TF at home but admitted to hospital for an acute illness were excluded from participation because of the “longer-term” nature of their therapy. An assumption was made that “short-term” TF would be the corresponding term for patients receiving TF in hospital in acute care. It quickly became apparent in discussions with the Dietitians who were assisting with the study that “short-term” was confusing as it excluded participants for whom TF had an impermanent intent but were receiving TF for greater than 30 days. The discrepancy was noted early in the data collection period and the confusion this term created with the recruitment protocol may have prevented some participants from being screened and thus potentially included in the study. Additionally, “short-term” TF was used in the “Information Letter for Participants” and although the term was not defined in the letter, its use in the title may have created confusion for participants. It was noted that those participants who received TF for longer than a month did not appear to restrict their comments to a defined period.

An additional limitation of the sample in this study was that the inclusion criteria were restricted to participants who were conscious and/or could communicate. Thus the sample excluded the experiences of individuals who were unconscious and/or could not speak for themselves and who may have had a very different experience. The challenges associated with including both of these patient populations in research and the limitations on generalizing results to the entire population of patients receiving TF have been noted by other authors (Persenius et al., 2009; Van Rosendaal & Verhoef, 1999; Verhoef & Van Rosendaal, 2001).

The exclusion of the family member's perspective was another notable limitation of this study. The purpose for excluding the perspective of loved ones was to stay focused on participants' perspectives of their experiences while also maintaining a narrow study scope given resource constraints (Morse, 2000). Because of the intimate nature of participants' and family members' relationships during a hospital admission and illness, it is unlikely that a truly homogeneous participant perspective was found. Further research with this population that included the family members' perspectives could provide another angle of vision for which to better understand the phenomenon of the experience with TF in acute care.

Given the small pool of patients available and the difficulties with recruiting participants for the current study, sampling was limited to convenience methods. With a larger pool of participants it may have been possible to use theoretical sampling techniques to intentionally select individuals who could expand upon the experiences reported and could verify the experiences of negative cases. For example, a “thin area” (Richards & Morse, 2007, p. 76) in the current study was the experience of individuals facing long-term TF who considered TF unnecessary. Pursuing individuals with this perspective may have added greater insight into the experience of coping with the new reality of remaining NPO and receiving a therapy that was in opposition to their goals. To counter these sampling limitations, participants were interviewed more than once with purposive questioning to elicit any different perspectives about the concepts being illuminated in the data. Replicating this research with a different sample may verify and expand upon the phenomenon of receiving TF in acute care.

Bias may have been introduced by selecting specific participants to complete additional interviews because of their ability to articulate a range of emotions associated with their TF experiences. This bias was countered by asking these participants questions that evolved from the themes generated by the wider pool of data. Additionally, because individuals who described themselves as being unsatisfied with TF in acute care did not complete a second interview, a more definitive understanding of their perspective of the themes ***A NECESSARY EVIL?*** and ***Resiliency*** remain unclear.

The participants knew both that the researcher was a Dietitian and, in some cases, that their HCPs were aware of their participation in the study, therefore this knowledge may have influenced their responses to questions about *Dietitian and HCP support*. This potential bias was countered by explaining to participants that the researcher would not discuss their responses with any members of the their health care team and that their participation in the study would have no bearing on their care in hospital. Other health professionals have examined a similar research question among the acutely ill population on TF and reported similar findings, although it is unclear if specific questions were asked about participant experiences with Dietitians and HCPs (Barbosa & Freitas, 2005; Persenius et al., 2009). Additionally, Dietitian authors conducting research on TF in the outpatient setting have reported primarily positive findings with respect to *Dietitian and HCP support* (Kwong et al., 2014; Osborne et al., 2012). In the current study, it was noted that participants interviewed in private hospital rooms or at home, did not differ remarkably in their responses about *Dietitian and HCP support* and their experiences with TF. Additionally, participants' in the current study described variability in the supportive practices of Dietitians and HCPs therefore the influence of the researcher being a Dietitian may have had little impact. Replicating the study with a different Dietitian researcher would verify or refute these findings.

The ID ***A NECESSARY EVIL?*** is limited to both the sample of participants constrained by convenience sampling techniques as well as the context of the participating units and hospitals in North Western Ontario, Canada. Although similar findings were noted among the Portuguese and Swedish participant samples in the studies by Barbosa and Freitas (2005) and Persenius et al. (2009), there were also differences among the findings that may account for sampling, context, or cultural differences. Thus, while the ID which emerged from the data from the current study does add to the wider body of knowledge about the phenomenon of the experience receiving TF in acute care; additional research on this topic conducted with a larger sample, in different regions and hospitals, as well as with the family members perspective could expand, modify, or extend these findings (Vandall-Walker, 2006).

Implications

The purpose of this study was to examine the patients' perspective with receiving TF in acute care within the disciplinary framework of Dietetics. In doing so, multiple, contextual realities of patients' perspectives about TF in acute care have been illuminated which are reflective of the practice realities with which many Dietitians will be familiar. These study findings reflect the need for reform in the ontological underpinnings of Dietetics from a primarily realist perspective to one that also embraces relativity so that Dietitians may comfortably embrace a patient-centered approach to care. Thus, the implications and recommendations for Dietetic research, practice, and teaching will be discussed with a mind towards change.

Implications for Research

This study has begun to fill the gap in knowledge about the deeper ***Meaning*** TF carries for the acutely ill patient and how this impacts his or her ability to cope with, and remain engaged in, the therapy. Additional exploration into the patients' experience with TF in acute care that is more widespread with a varied sample in different locations would be beneficial to enhance the extant knowledge about this topic. Canadian research conducted in other provinces as well as in different hospital settings would help to verify and expand upon the current findings, as well as to flush out any cultural characteristics that may impact the patients' experience.

The current study has illuminated new angles about the patient's experience with TF in acute care that demands more focused research to assist Dietitians and HCPs with the knowledge necessary to be truly patient-centered. Furthermore, families' perspectives of caring for a loved one in acute care on TF and their information and support needs are currently missing from the wider body of knowledge about this phenomenon. It is recommended that the following research questions be explored:

- How do family members of patients receiving tube feeding in acute care, describe their experiences?
- How do patients' on TF in acute care describe their coping?
- What comparisons can be made between patients' and Dietitians' goals for tube feeding in acute care?
- What are Dietitians', Nurses', and Physicians' beliefs about presenting different therapeutic nutritional options to patients with compromised oral intake? How do Dietitians, Nurses, and Physicians describe their readiness to assist patients with clarifying their values and preferences about these options?
- What are Dietitians' beliefs about providing comforting, appropriate physical touch during a patient encounter in the hospital setting?
- How does the provision of comforting and appropriate physical touch by Dietitians, Nurses, and Physicians affect the patients' experience with TF in acute care?
- What are Dietitians' perceptions of the application of the 3CNE Framework to the care of acutely ill patients on TF?
- How does the application of the 3CNE Framework by Dietitians influence the patient's experiences with TF in acute care?

Implications for Practice

The disconnect between the need for Dietitians to provide better patient-centered care to acutely ill patients' on TF and Dietitians' lack of clarity on how to do so, is evidenced by the findings from the current study and the existing literature on Dietitians and patient-centered care (MacLellan & Berenbaum, 2003). The findings from the current study suggest that change is required at both the teaching and practice level. The following are the implications to Dietetic practice with recommendations:

- The findings from this study reinforce that significant discomfort with TF therapy remains for patients in acute care. It is recommended that Dietitians work with the interprofessional team to review both practical and emotional strategies that could mitigate patient discomfort, then develop an implementation and evaluation plan.
- For Dietitians to be considered active and effective patient-centered providers of TF care, they would benefit from skill building workshops on collaborative communication that incorporate the patients' perspectives, to improve their listening and interviewing skills as well as how to establish rapport with patients.
- The initial nutrition assessment of patients' requiring TF could incorporate questions about the patient's values, beliefs, and goals to understand the ***Meaning*** nutrition and artificial nutrition support therapies holds for them. This information could then be considered in the development of a mutually acceptable care plan with realistic clinical outcomes in collaboration with the patient.
- It is recommended that Dietitians lead a discussion with the interprofessional team about the available therapeutic nutritional alternatives for patients with compromised oral intake with a goal to determine team receptivity with offering

patients treatment choices in different clinical situations. Following this step, it is recommended that all applicable therapeutic nutritional options be explored and thoroughly discussed with the patient prior to, and during, TF therapy.

- As patients require regular and comprehensive information about TF, it is recommended that Dietitians develop and distribute a brief but comprehensive handout for patients and families on what to expect with TF while in hospital. This information could be supplemented with regular offers for more information during the course of TF, including the expected duration of the therapy.
- It is recommended that Dietitians collaborate with patients' families to assist with transitioning TF patients back to oral intake. For example, by recommending that family members provide a consistent variety of food items that supplement the hospital diet.

Implications for Education

With the traditional focus within the discipline being on the science of delivering foods and nutrition, Dietetic students are ill-prepared for the complexities of practice including addressing patients' emotional and social concerns with aversive nutritional therapies such as TF during an acute illness (Gingras, de Jonge, & Purdy, 2010). The following are Dietetic teaching implications and recommendations stemming from this thesis:

- Improving Dietetic students' emotional awareness in the context of clinical practice could be promoted in the classroom and clinical settings to promote greater patient-centeredness. In so doing, students may become better prepared for, and more responsive to, the myriad of patients' physical, emotional, and social needs that could lead to better outcomes such as improved health through comfort and rest as well as satisfaction with the care provided. To this end, Canadian Dietetic educators are beginning to incorporate the arts and humanities into Dietetic pedagogy (Morley, 2011), a curriculum change that could be considered in all university Dietetic programs.

- Providing formal training for interpersonal counseling skills at the university level and in practicum settings, rather than assume Dietitian preceptors will provide teaching on this essential skill during placement, may be beneficial.
- Finally, the patients' perspective about receiving TF in acute care could be incorporated throughout clinical teaching courses and texts. This curriculum change may provide Dietetic students with an understanding of the impact aversive nutritional therapies have on the human experience, sensitizing them towards an appropriate expectation for clinical outcomes and approach to care.

Summary

In this chapter has been provided a discussion of the major findings of the current study, ***A NECESSARY EVIL?***, ***DISCOMFORT***, ***NECESSITY***, ***Meaning***, ***Resilience***, and ***Trust,*** compared and contrasted with the extant literature on TF in acute care and TF in the outpatient setting and including the limitations and implications of this study. The findings of this study supported, differed from, and added to the current body of knowledge about the patients' experience with TF in acute care, highlighting the rationale for patients’ reactions to the TF experience and what Dietitians and HCPs can do to support and improve the patients’ experience.

The study limitations were primarily related to sample limitations associated with the context within which this research was conducted. The implications of this research for the teaching and practice of Dietitians is significant as it is the first study on TF in acute care to provide detailed descriptions about the patients’ perception of *Dietitian and HCP support,* as well as recommendations for improvement. Finally, although this study contributes new knowledge to the phenomenon, additional research is required to verify and extend the understanding of the patients’ experience with TF in acute care.

CHAPTER 6

CONCLUSION

The interplay of the multiple factors included in the Interpretive Description, ***A NECESSARY EVIL*** explained the acutely ill patients' experience with TF, including the ***Meaning*** attributed to TF (beyond ***NECESSITY***), the ***Trust*** placed in health care providers, TF ***DISCOMFORT***, and participant ***Resilience*** in the face of this ***DISCOMFORT***. The impact of these inter-related factors influenced participants' varying perceptions of the ***NECESSITY*** for TF and their responses to the therapy. These findings had not previously been presented as comprehensively, both conceptually or schematically in the English language literature. Thus this study provides new insight into the interrelated factors influencing the phenomenon of receiving TF in acute care.

For Dietitians and HCPs working with patients receiving TF in acute care, there is a need to understand the patients' perspective of his or her experiences in order to adapt practices and improve the overall experiences for this patient population. Study findings have provided an explanation of patients' descriptions about receiving TF in acute care from a Canadian perspective, illuminating the multiple factors that interact to affect the patient's acceptance of, and engagement with, this therapy. As this study was conducted with a lens towards patient-centered care, the detailed descriptions of patients' information and support needs may begin to inform Dietitians and HCPs as to how they can adapt their practices to be more supportive. Additionally, findings have illuminated the research required to understand the various angles of the patients' experience with TF while also highlighting the need for Dietetic curriculum changes.

For many patients in acute care, TF remains a therapy with substantial benefits to health and recovery from serious illness. The resilience enabling patients to be tolerant of the discomfort associated with TF requires ongoing support and teaching from Dietitians, HCPs, and family members. This study has illuminated some of the specific information and support needs patients require. However this must be considered within the context of the meaning patients have attributed to the therapy to ensure support is appropriately directed.

This study is the first in the English language to examine why patients feel TF is unnecessary for their condition while revealing the potential actions Dietitians and HCPs could take to increase patients' comfort during illness and hospitalization. Comfort is clearly an important determinant of acutely ill patients' satisfaction with nutritional therapies, but is inhibited by a lack of understanding about the meaning patients attribute to TF, their resilience, and the trust held in Dietitians and HCPs. To be patient-centered, Dietitians and HCPs need to incorporate patients' values, beliefs, and goals into their nutrition care plan and support resilient behaviours, while being flexible with expectations and goals for nutritional therapies.

Although there were limitations associated with this study related to sampling and recruitment, findings nonetheless provide more insight into patients' perspective of TF therapy in acute care, filling a gap in knowledge about this phenomenon. It is hoped that the findings of this study will not only resonate with Dietitians and HCPs caring for patients on TF in acute care, but will also begin to influence the way Dietetic students are educated and what the appropriate approach to TF care could be in the practice setting. Additional research illuminating family members, Dietitians' and HCPs' perceptions of caring for patients on TF in acute care will add to the body of knowledge about this phenomenon, leading ultimately to a more beneficial and satisfactory experience for those who are nutritional compromised in acute care.

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Appendix A: Table 1. Literature Review Table

Author	Country	Participant Location	Purpose, Sample, Method	Key Findings
Bannerman, Pendlebury, Philips and Ghosh (2000)	United Kingdom	Both in home and hospital	To determine the impact of gastrostomy on Health Related Quality of Life (QAL). 55 patients, previously received or on gastrostomy TF, living at home; and 54 patients with a gastrostomy TF in hospital or living at home. Quantitative, cross-sectional and prospective cohort, longitudinal design with two standardized questionnaires.	Gastrostomy feeding reported as having a positive impact for 55% of all patients. Deficiencies in patient's perception of their physical abilities were noted. 30-40% of patients were not confident that they were receiving adequate nutrition.
Bruning, Halling, Kappner, Klein Poelhuis, Kobashi-Schoot, and Schouwenburg (1988)	The Netherlands	Hospital	To prospectively assess the nutritional status and well-being of post-operative NG feeding in patients with head and neck cancer. 20 patients on NG TF. Quantitative, prospective observational and longitudinal study. "Well-being" was investigated using two standardized, self-administered questionnaires.	By day seven of TF: >50% of patients complained of GI discomforts, physical discomforts associated with the feeding tube, and a number of sensory distresses associated with being deprived of food and liquids as well as being unable to sleep. By day 21 of TF: discomfort associated with being deprived of food remained for >50% of participants.
Brotherton, Abbott and Aggett (2006)	United Kingdom	Home	To characterize, from the perspectives both of the patients and their caregivers, how the provision of enteral nutrition via PEG impacts the daily life and QAL of adult patients. 15 patients on PEG TF and 19 caregivers. Cross-sectional qualitative using semi-structured interviews.	QAL reported by the majority of patients as acceptable. Themes reported: relief of pressure to consume an oral diet; disturbed sleep; restricted ability to go out; restricted choice of clothing; difficulties finding a place to feed; missing being able to eat and drink; social occasions; negative attitudes of others towards feeding; the burden on family members and physical and technical difficulties with PEG feedings.
Brotherton and Abbott (2009)	United Kingdom	Home	To explore patients' and their caregivers perceptions of the adequacy of the information provided and their subsequent involvement in the decision making process for PEG tube insertion. 16 patients on PEG TF and 27 caregivers. Cross-sectional qualitative using	The majority of participants reported receiving insufficient information regarding the PEG. Themes reported: poor communication; lack of information; inappropriate information; attitudes of health care professionals; and exclusion.

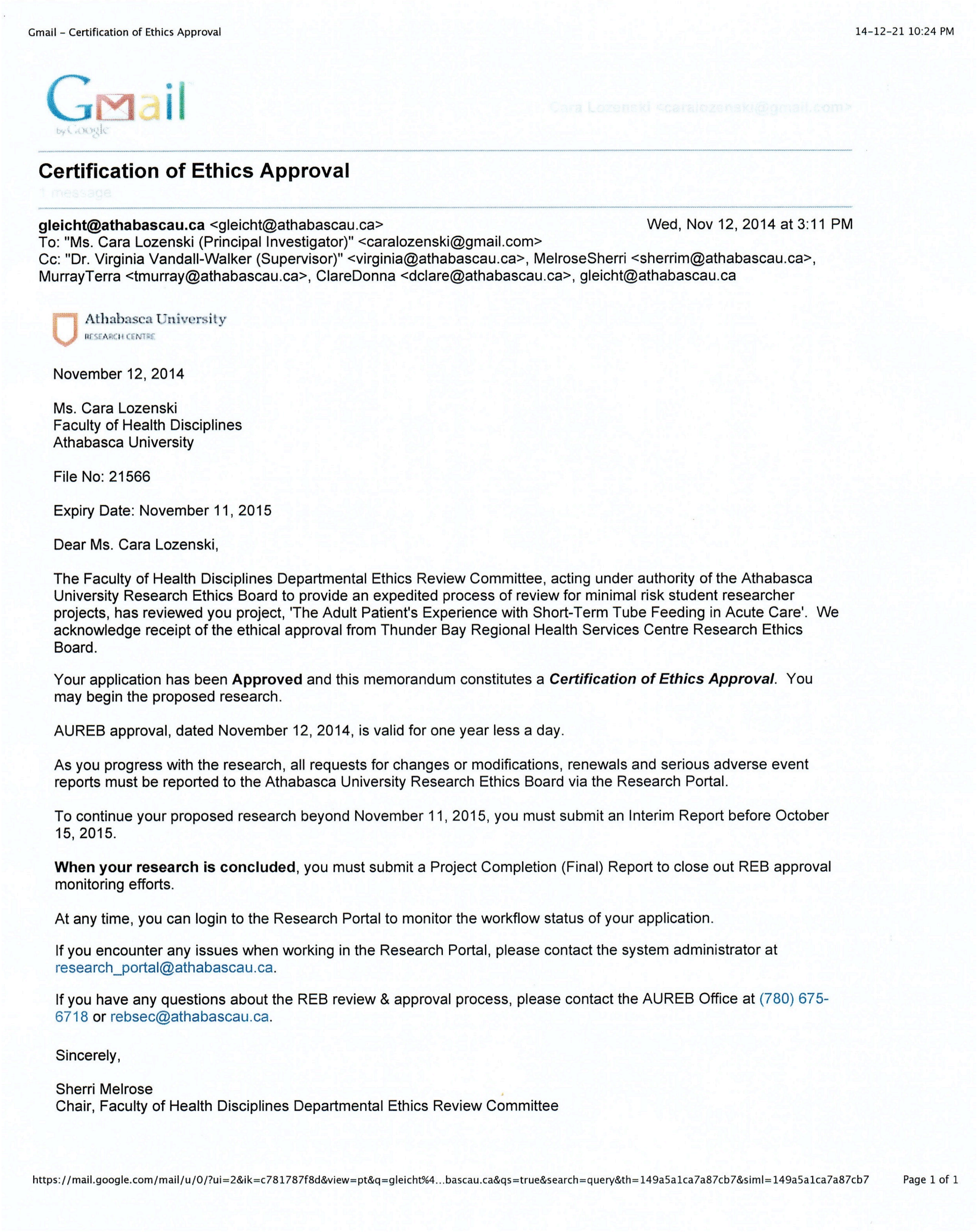
			semi-structured interviews.	
Jordan, Philpin, Warring, Cheung, and Williams (2006)	United Kingdom	Home	To enhance understanding of the patients' experience on PEG feeding. 20 patients on PEG TF. Qualitative using concurrent, nested, mixed-method design using semi-structured interviews, structured symptom-rating scale, and generic QAL measure.	Both physical and mental health scores were low for all patients. PEG feeding reported as life saving but the burden of treatment was unanticipated for some. Themes reported: physical restrictions on mobility; technical problems with the PEG; treatable and ongoing gastrointestinal problems; and difficulties with care by non-specialist services.
Kayser-Jones (1990)	United States	Nursing home	To investigate the attitudes of patients, family members, nurses and physicians toward the use of NG tube feedings in three nursing homes. 103 nursing home patients not receiving TF and 107 family members. Qualitative, anthropologic field study with participant observation, event analysis, and in-depth interviews.	The majority of patients and family members favored the use of TF if faced with the decision because of the value they placed on life. Fear of adverse health effects from the feeding tube; assumptions TF is a punishment or a therapy for the mentally ill; and unhappiness with life in the nursing home were reasons for not wanting TF among patients.
Majid, Emery and Whelan (2012)	United Kingdom	Hospital	To investigate patients', nurses', and dietitians' definitions of diarrhea during TF, the attitudes of nurses toward it, and the management practices of nurses and dietitians in response to diarrhea during TF. 22 hospitalized patients on NG or NJ TF, 57 nurses and, 33 dietitians caring for the patients. Quantitative, cross-sectional design using a structured questionnaire.	Patients have different definitions and attitudes toward diarrhea during TF from those of nurses and dietitians.
Mayre-Chilton, Talwar, Goff (2011)	United Kingdom	Home	To understand the daily impact of gastrostomy feeding on head and neck cancer patients and their caregivers to identify improvements to services. 6 patients on gastrostomy TF and 3 caregivers. Qualitative using self-administered questionnaires and a focus group.	Expressed the benefits of retaining a support network for rehabilitation with the hospital-based specialist team and that the gastrostomy tube improved survival. Reported themes: developing positive coping strategies; preventing nutritional decline; tube dependency; dentures; finance; active care; and psychological support.
Morrison et al.	United	Hospital	To determine whether reliable	NG tube insertion was considered

(1998)	States		and valid rankings of pain and discomfort resulting from common hospital procedures encountered by advanced dementia patients could be developed from interviews with cognitively intact adults. 100 hospitalized patients who experienced NG tube placement and other common hospital procedures. Quantitative, using a 10 and 5-point numeric rating scale questionnaire.	moderately painful and ranked the most uncomfortable.
Osborne, Collin, Posluns, Stokes, Vandenbussche. (2012)	Central Canada	Home	To learn about the experience of patients living with a PEG tube. 41 patients previously on PEG TF and 10 prospectively receiving PEG TF Mixed methods using a semi-structured questionnaire.	Positive to neutral effect on QAL, noted to be advantageous and life saving for patients who completed PEG feeding treatment. For those remaining on PEG feedings, reports included: negative effect on family, and social life; negatively impacted by attitudes of others toward their PEG; tube leakage; sleep disruption; and negative effect on intimate relationships and appearance.
Padilla et al. (1979)	United States	Hospital	To determine the type, incidence, and subjective level of distress experiences associated with NG tube feeding. 30 patients on NG TF. Quantitative, using two structured questionnaires.	The majority of patients reported >20 common and distressful experiences associated with TF, categorized as sensory irritations and sensory deprivation.
Padilla and Grant (1985)	United States	Hospital	To compare the effects of different patient teaching approaches on psychological distress, motivation, and perceived control during TF. 35 patients on NG TF Quantitative, randomized, experimental, pre-post-test design using four different patient education films.	Anxiety and discomfort decreased the most with education on sensory experiences and the TF procedure. Sensory rather than coping behaviour information is more likely to be associated with higher levels of perceived control over TF. Perceived coping ability is more likely to be associated with willingness to repeat the TF experience.
Persenius et al. (2009)	Sweden	Hospital-ICU	To provide a theoretical understanding of nutritional experiences of patients with enteral nutrition. 14 patients admitted to the ICU	The core category ‘grasping nutrition during the recovery process’ was reflected in and related to the categories: ‘facing nutritional changes’, ‘making sense of the nutritional situation’ and ‘being involved with nutritional care’. Patients shifted between

			Grounded theory developed from 21 patient observations and 21 individual interviews.	worry, fear, and failure, and relief and hope.
Rickman (1998)	United Kingdom	Home	To explore the psychological effects of PEG feeding on both patients and caregivers. 12 patients on PEG feeding and eight caregivers. Phenomenological, qualitative approach with some quantitative measurement tools.	Reported themes: family/relationships; eating and PEG; equipment/problems with; help/information and support; time/limitations; beliefs/personal comments; and feelings. A significant level of depression and stress was found among patients who also expressed gratitude for the nutritional benefits of the PEG. Expressed a need for more initial factual information and for ongoing practical and psychological support.
Roberge et al. (2000)	France	Home	To evaluate the impact of home TF on QAL 30 patients on NG or gastrostomy TF at home. Quantitative, longitudinal survey using self-administered questionnaires.	QAL and physical function improved slightly between weeks one and four of TF initiation. General tolerance to the physical feeding technique but psychologically less tolerated with the majority longing to have the tube removed.
Scolapio, Picco, and Tarrosa. (2002)	United States	Hospital	To evaluate patient preference for NG versus IV feeding. 101 hospitalized patients not receiving TF compared to 98 healthy outpatients. Quantitative, using a controlled, comparative design and self-administered questionnaire.	The majority would prefer IV to tube feeding given the perception of comfort associated with these interventions.
Senft, Fietkau, Iro, Sailer, and Sauer (1993)	Germany	Home	To determine the influence of supportive nutritional therapy via PEG on the quality of life of cancer patients. 75 outpatients with head and neck cancer eating orally without a PEG compared to 27 head and neck cancer outpatients on PEG TF. Quantitative, prospective, comparative, observational study using a self-administered structured questionnaire.	QAL score for PEG patients did not deteriorate during treatment compared to the orally fed patient group.
Verhoef, Guido, and Van	Western Canada	Home	To assess a range of physical, psychological, and social	Patients stated they would have the PEG again because it contributed to their survival;

Rosendaal. (2001)			outcomes related to PEG feeding. 10 patients on PEG TF and their caregivers. Mixed-methods, longitudinal survey using semi-structured interviews and questionnaire.	reported increased physical well-being, convenience, and independence but noted general discomforts and complications related to the PEG. Caregivers perceived that the patient's QAL was not necessarily enhanced with regards to activity level, self-care, and physical/mental well being.
Walker (2005)	United States	Home	To address the social and symbolic meaning of food with exploration into what happens on a micro-interactional level when people lose the ability to eat. 16 patients and their caregivers on PEG TF. Qualitative, using interviews and a semi-structured questionnaire.	Experienced social bereavement and an undesirable change in identify secondary to the loss of the ability to eat, inability to prepare and participate in meals, and the physical side effects of the PEG tube.

Appendix B: Athabasca University Final Research Ethics Approval



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Gmail by Google

Cara Lozenski <caralozenski@gmail.com>

Certification of Ethics Approval

1 message

gleicht@athabascau.ca <gleicht@athabascau.ca> Wed, Nov 12, 2014 at 3:11 PM
To: "Ms. Cara Lozenski (Principal Investigator)" <caralozenski@gmail.com>
Cc: "Dr. Virginia Vandall-Walker (Supervisor)" <virginia@athabascau.ca>, MelroseSherri <sherrim@athabascau.ca>, MurrayTerra <tmurray@athabascau.ca>, ClareDonna <dclare@athabascau.ca>, gleicht@athabascau.ca

Athabasca University
RESEARCH CENTRE

November 12, 2014

Ms. Cara Lozenski
Faculty of Health Disciplines
Athabasca University

File No: 21566

Expiry Date: November 11, 2015

Dear Ms. Cara Lozenski,

The Faculty of Health Disciplines Departmental Ethics Review Committee, acting under authority of the Athabasca University Research Ethics Board to provide an expedited process of review for minimal risk student researcher projects, has reviewed you project, 'The Adult Patient's Experience with Short-Term Tube Feeding in Acute Care'. We acknowledge receipt of the ethical approval from Thunder Bay Regional Health Services Centre Research Ethics Board.

Your application has been **Approved** and this memorandum constitutes a ***Certification of Ethics Approval***. You may begin the proposed research.

AUREB approval, dated November 12, 2014, is valid for one year less a day.

As you progress with the research, all requests for changes or modifications, renewals and serious adverse event reports must be reported to the Athabasca University Research Ethics Board via the Research Portal.

To continue your proposed research beyond November 11, 2015, you must submit an Interim Report before October 15, 2015.

When your research is concluded, you must submit a Project Completion (Final) Report to close out REB approval monitoring efforts.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research_portal@athabascau.ca.

If you have any questions about the REB review & approval process, please contact the AUREB Office at (780) 675-6718 or rebsec@athabascau.ca.

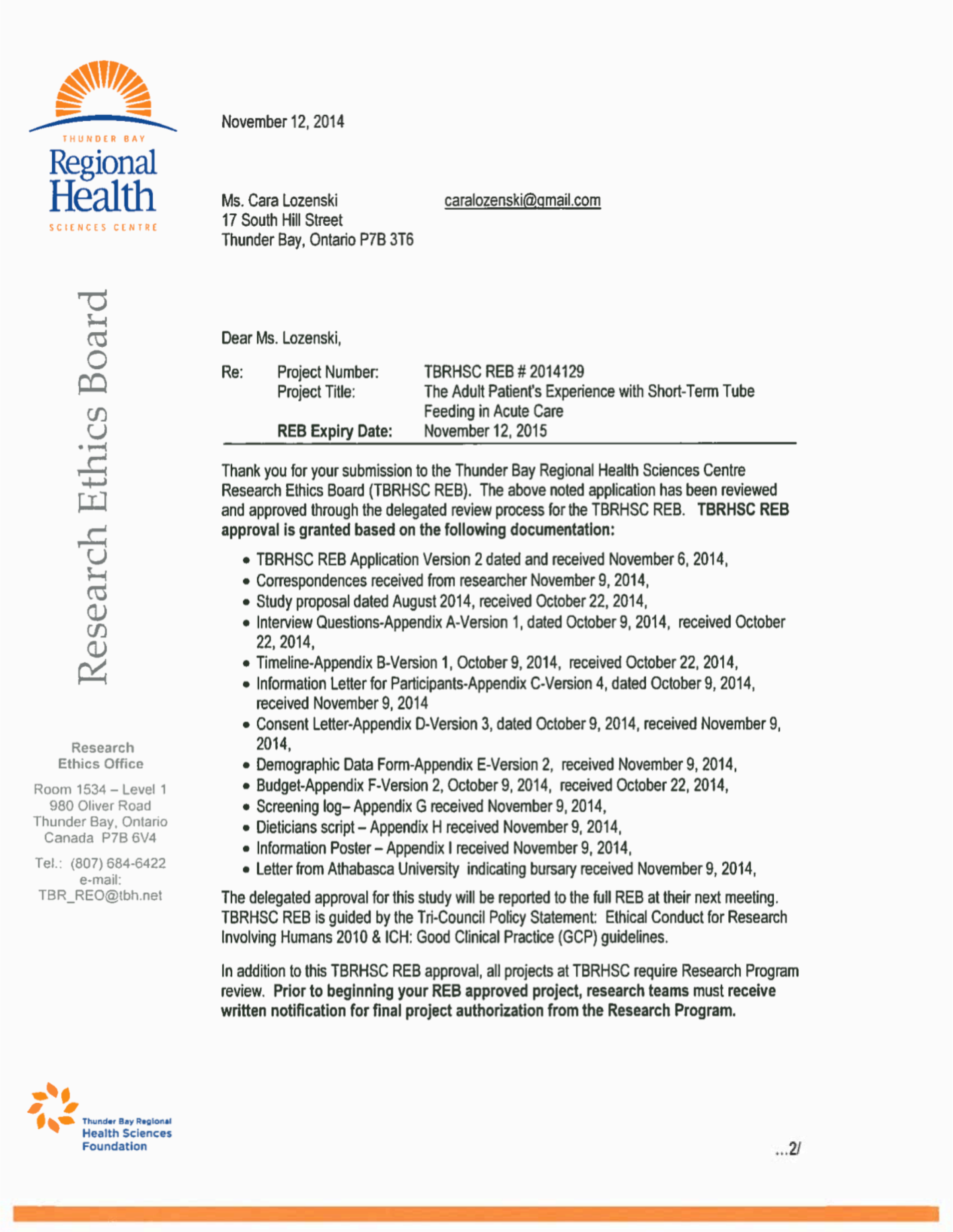
Sincerely,

Sherri Melrose
Chair, Faculty of Health Disciplines Departmental Ethics Review Committee

https://mail.google.com/mail/u/0/?ui=2&ik=c781787f8d&view=pt&q=gleicht%4...bascau.ca&qs=true&search=query&th=149a5a1ca7a87cb7&siml=149a5a1ca7a87cb7 Page 1 of 1

Appendix C: Thunder Bay Regional Health Science Centre

Final Research Ethics Approval



THUNDER BAY
Regional
Health
SCIENCES CENTRE

Research Ethics Board

Research
Ethics Office

Room 1534 – Level 1
980 Oliver Road
Thunder Bay, Ontario
Canada P7B 6V4

Tel.: (807) 684-6422
e-mail:
TBR_REO@tbh.net

November 12, 2014

Ms. Cara Lozenski caralozenski@gmail.com
17 South Hill Street
Thunder Bay, Ontario P7B 3T6

Dear Ms. Lozenski,

Re:		
	Project Number:	TBRHSC REB # 2014129
	Project Title:	The Adult Patient's Experience with Short-Term Tube Feeding in Acute Care
	REB Expiry Date:	November 12, 2015

Thank you for your submission to the Thunder Bay Regional Health Sciences Centre Research Ethics Board (TBRHSC REB). The above noted application has been reviewed and approved through the delegated review process for the TBRHSC REB. **TBRHSC REB approval is granted based on the following documentation:**

- TBRHSC REB Application Version 2 dated and received November 6, 2014,
- Correspondences received from researcher November 9, 2014,
- Study proposal dated August 2014, received October 22, 2014,
- Interview Questions-Appendix A-Version 1, dated October 9, 2014, received October 22, 2014,
- Timeline-Appendix B-Version 1, October 9, 2014, received October 22, 2014,
- Information Letter for Participants-Appendix C-Version 4, dated October 9, 2014, received November 9, 2014
- Consent Letter-Appendix D-Version 3, dated October 9, 2014, received November 9, 2014,
- Demographic Data Form-Appendix E-Version 2, received November 9, 2014,
- Budget-Appendix F-Version 2, October 9, 2014, received October 22, 2014,
- Screening log– Appendix G received November 9, 2014,
- Dieticians script – Appendix H received November 9, 2014,
- Information Poster – Appendix I received November 9, 2014,
- Letter from Athabasca University indicating bursary received November 9, 2014,

The delegated approval for this study will be reported to the full REB at their next meeting. TBRHSC REB is guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2010 & ICH: Good Clinical Practice (GCP) guidelines.

In addition to this TBRHSC REB approval, all projects at TBRHSC require Research Program review. **Prior to beginning your REB approved project, research teams must receive written notification for final project authorization from the Research Program.**

Thunder Bay Regional
Health Sciences
Foundation

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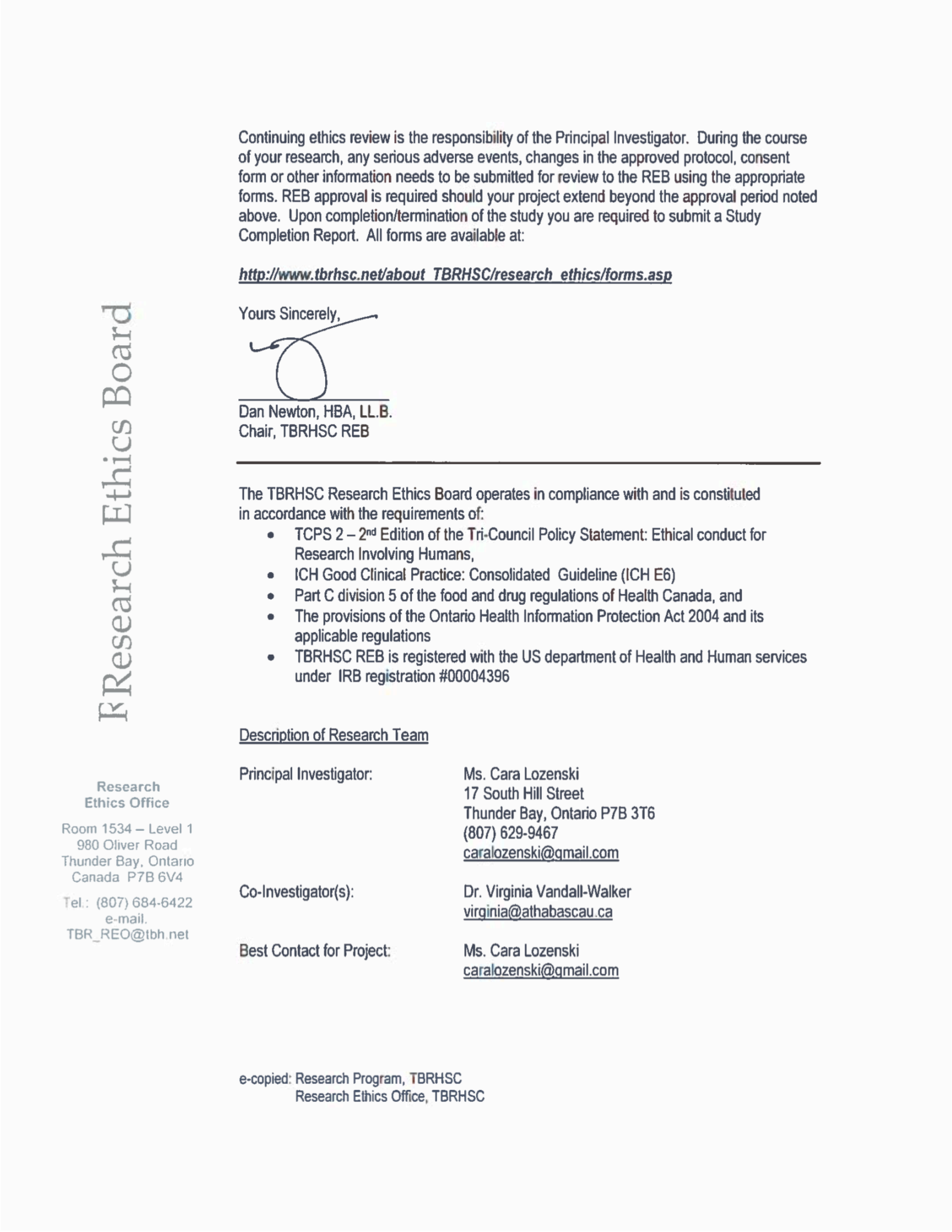


Research Ethics Board

Research
Ethics Office

Room 1534 – Level 1
980 Oliver Road
Thunder Bay, Ontario
Canada P7B 6V4

Tel.: (807) 684-6422
e-mail.
TBR_REO@tbh.net

Continuing ethics review is the responsibility of the Principal Investigator. During the course of your research, any serious adverse events, changes in the approved protocol, consent form or other information needs to be submitted for review to the REB using the appropriate forms. REB approval is required should your project extend beyond the approval period noted above. Upon completion/termination of the study you are required to submit a Study Completion Report. All forms are available at:

http://www.tbrhsc.net/about_TBRHSC/research_ethics/forms.asp

Yours Sincerely,

Dan Newton, HBA, LL.B.
Chair, TBRHSC REB

The TBRHSC Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of:

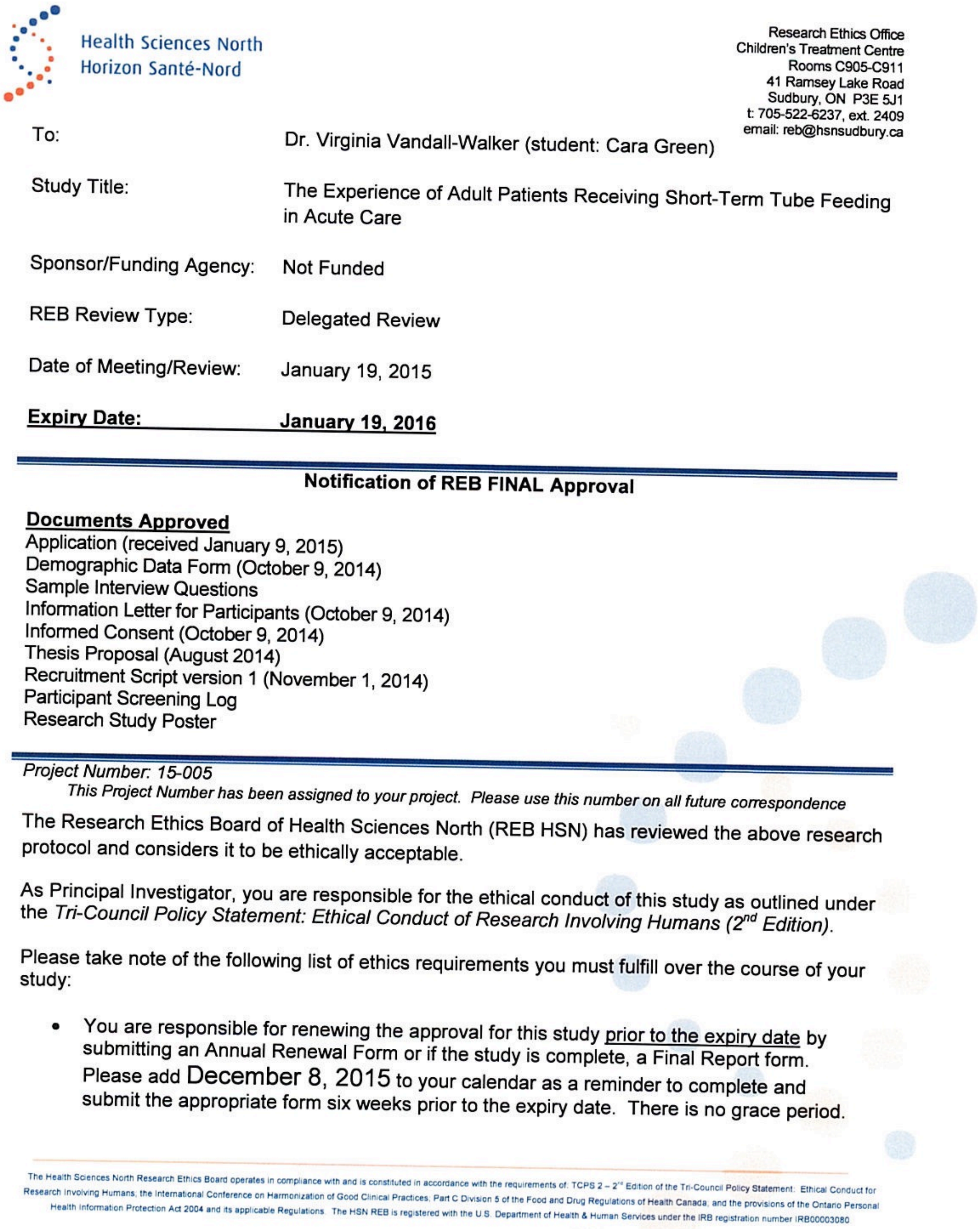
- TCPS 2 – 2nd Edition of the Tri-Council Policy Statement: Ethical conduct for Research Involving Humans,
- ICH Good Clinical Practice: Consolidated Guideline (ICH E6)
- Part C division 5 of the food and drug regulations of Health Canada, and
- The provisions of the Ontario Health Information Protection Act 2004 and its applicable regulations
- TBRHSC REB is registered with the US department of Health and Human services under IRB registration #00004396

Description of Research Team

Principal Investigator:	Ms. Cara Lozenski 17 South Hill Street Thunder Bay, Ontario P7B 3T6 (807) 629-9467 caralozenski@gmail.com
Co-Investigator(s):	Dr. Virginia Vandall-Walker virginia@athabascau.ca
Best Contact for Project:	Ms. Cara Lozenski caralozenski@gmail.com

e-copied: Research Program, TBRHSC
Research Ethics Office, TBRHSC

Appendix D: Health Science North Final Research Ethics Approval



Health Sciences North
Horizon Santé-Nord

Research Ethics Office
Children's Treatment Centre
Rooms C905-C911
41 Ramsey Lake Road
Sudbury, ON P3E 5J1
t: 705-522-6237, ext. 2409
email: reb@hsnsudbury.ca

To: Dr. Virginia Vandall-Walker (student: Cara Green)

Study Title: The Experience of Adult Patients Receiving Short-Term Tube Feeding in Acute Care

Sponsor/Funding Agency: Not Funded

REB Review Type: Delegated Review

Date of Meeting/Review: January 19, 2015

Expiry Date: January 19, 2016

Notification of REB FINAL Approval

Documents Approved
Application (received January 9, 2015)
Demographic Data Form (October 9, 2014)
Sample Interview Questions
Information Letter for Participants (October 9, 2014)
Informed Consent (October 9, 2014)
Thesis Proposal (August 2014)
Recruitment Script version 1 (November 1, 2014)
Participant Screening Log
Research Study Poster

Project Number: 15-005
This Project Number has been assigned to your project. Please use this number on all future correspondence

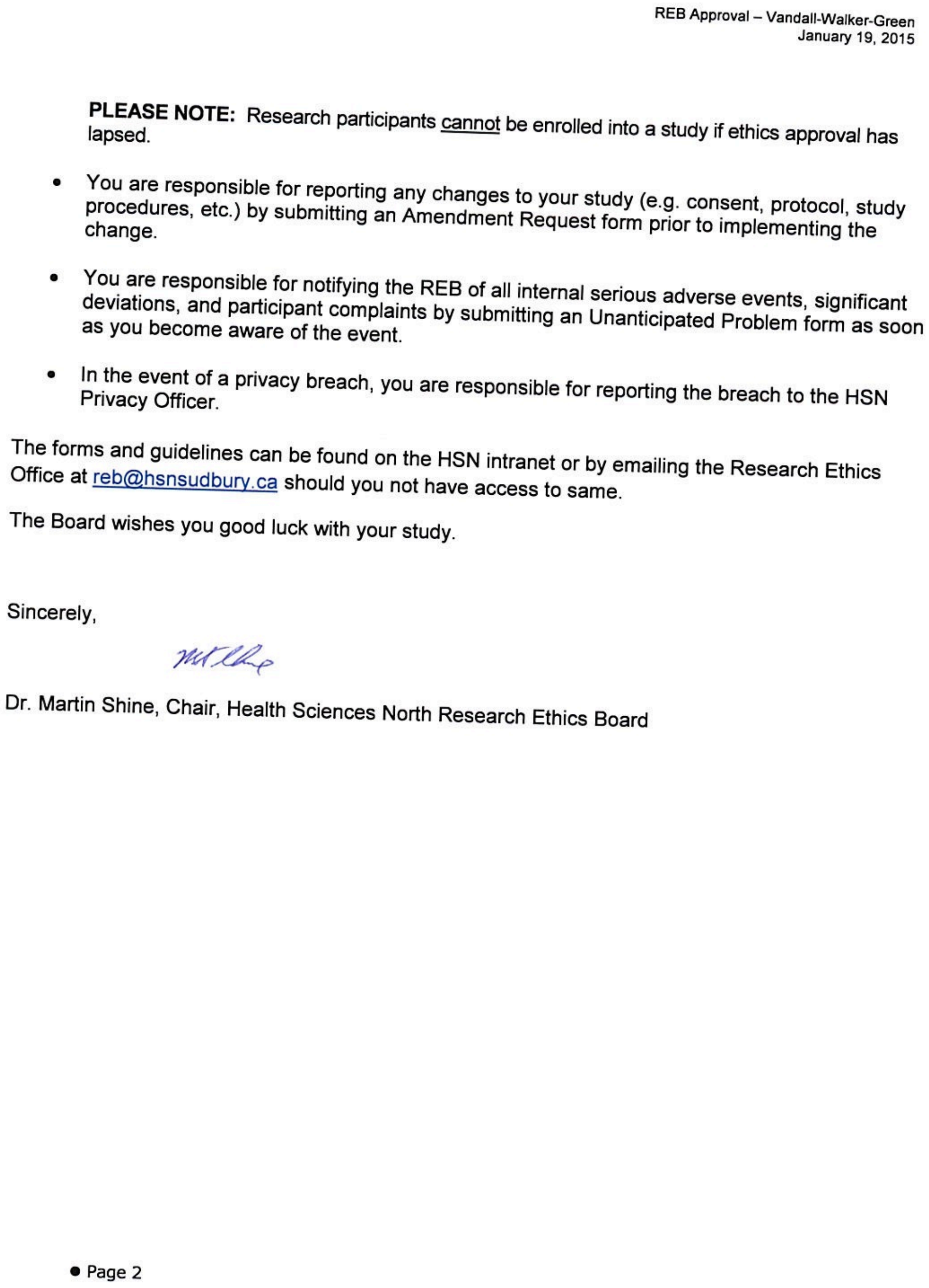
The Research Ethics Board of Health Sciences North (REB HSN) has reviewed the above research protocol and considers it to be ethically acceptable.

As Principal Investigator, you are responsible for the ethical conduct of this study as outlined under the *Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans (2nd Edition)*.

Please take note of the following list of ethics requirements you must fulfill over the course of your study:

- You are responsible for renewing the approval for this study prior to the expiry date by submitting an Annual Renewal Form or if the study is complete, a Final Report form. Please add December 8, 2015 to your calendar as a reminder to complete and submit the appropriate form six weeks prior to the expiry date. There is no grace period.

The Health Sciences North Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: TCPS 2 – 2nd Edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. The HSN REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB00003080



REB Approval – Vandall-Walker-Green
January 19, 2015

PLEASE NOTE: Research participants <u>cannot</u> be enrolled into a study if ethics approval has lapsed.

- You are responsible for reporting any changes to your study (e.g. consent, protocol, study procedures, etc.) by submitting an Amendment Request form prior to implementing the change.
- You are responsible for notifying the REB of all internal serious adverse events, significant deviations, and participant complaints by submitting an Unanticipated Problem form as soon as you become aware of the event.
- In the event of a privacy breach, you are responsible for reporting the breach to the HSN Privacy Officer.

The forms and guidelines can be found on the HSN intranet or by emailing the Research Ethics Office at reb@hsnsudbury.ca should you not have access to same.

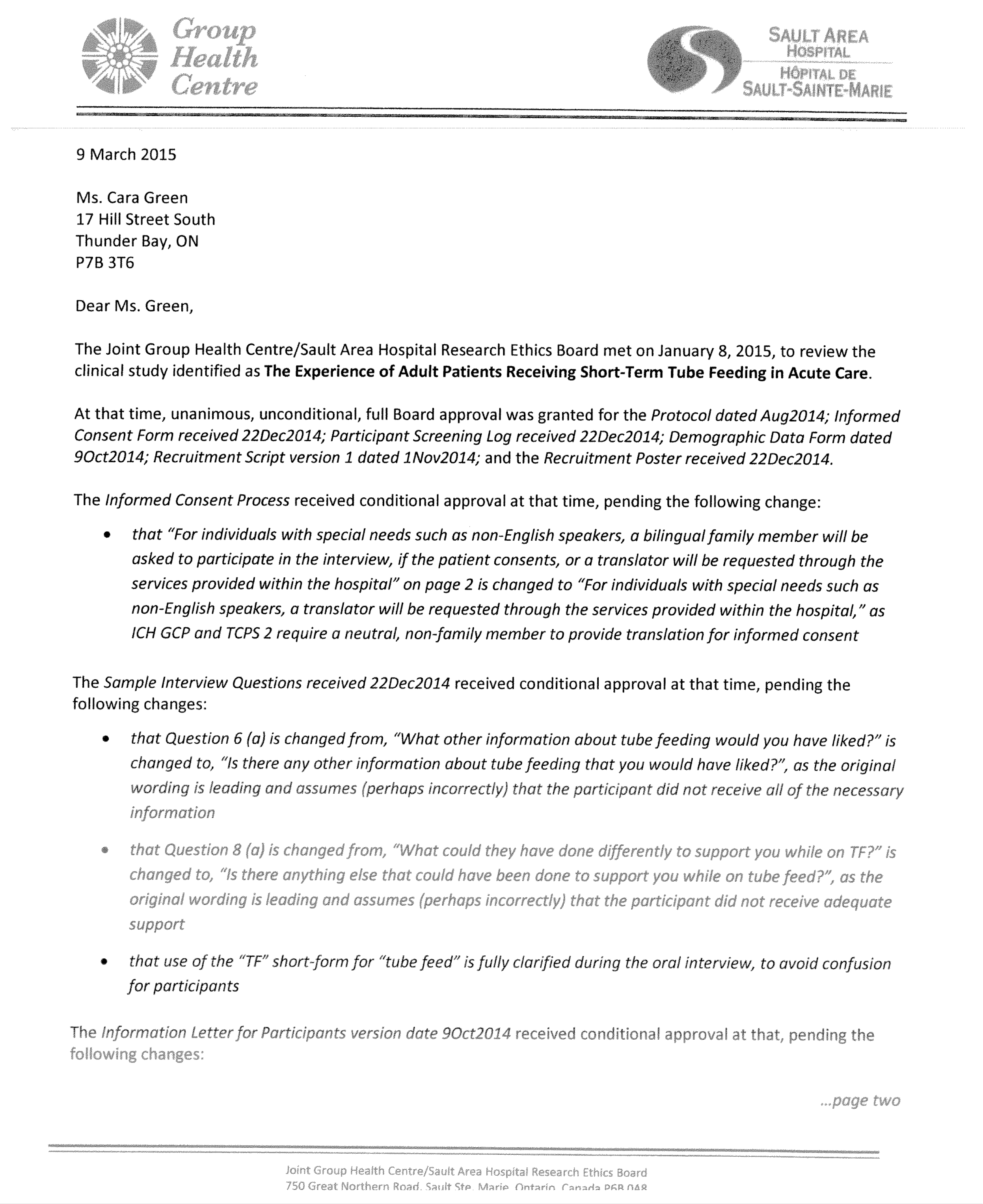
The Board wishes you good luck with your study.

Sincerely,

Dr. Martin Shine, Chair, Health Sciences North Research Ethics Board

● Page 2

Appendix E: Sault Area Hospital Final Research Ethics Approval



Group Health Centre

SAULT AREA HOSPITAL
HÔPITAL DE SAULT-SAINTE-MARIE

9 March 2015

Ms. Cara Green
17 Hill Street South
Thunder Bay, ON
P7B 3T6

Dear Ms. Green,

The Joint Group Health Centre/Sault Area Hospital Research Ethics Board met on January 8, 2015, to review the clinical study identified as **The Experience of Adult Patients Receiving Short-Term Tube Feeding in Acute Care**.

At that time, unanimous, unconditional, full Board approval was granted for the *Protocol dated Aug2014; Informed Consent Form received 22Dec2014; Participant Screening Log received 22Dec2014; Demographic Data Form dated 9Oct2014; Recruitment Script version 1 dated 1Nov2014;* and the *Recruitment Poster received 22Dec2014.*

The *Informed Consent Process* received conditional approval at that time, pending the following change:

- *that "For individuals with special needs such as non-English speakers, a bilingual family member will be asked to participate in the interview, if the patient consents, or a translator will be requested through the services provided within the hospital" on page 2 is changed to "For individuals with special needs such as non-English speakers, a translator will be requested through the services provided within the hospital," as ICH GCP and TCPS 2 require a neutral, non-family member to provide translation for informed consent*

The *Sample Interview Questions received 22Dec2014* received conditional approval at that time, pending the following changes:

- *that Question 6 (a) is changed from, "What other information about tube feeding would you have liked?" is changed to, "Is there any other information about tube feeding that you would have liked?", as the original wording is leading and assumes (perhaps incorrectly) that the participant did not receive all of the necessary information*
- *that Question 8 (a) is changed from, "What could they have done differently to support you while on TF?" is changed to, "Is there anything else that could have been done to support you while on tube feed?", as the original wording is leading and assumes (perhaps incorrectly) that the participant did not receive adequate support*
- *that use of the "TF" short-form for "tube feed" is fully clarified during the oral interview, to avoid confusion for participants*

The *Information Letter for Participants version date 9Oct2014* received conditional approval at that, pending the following changes:

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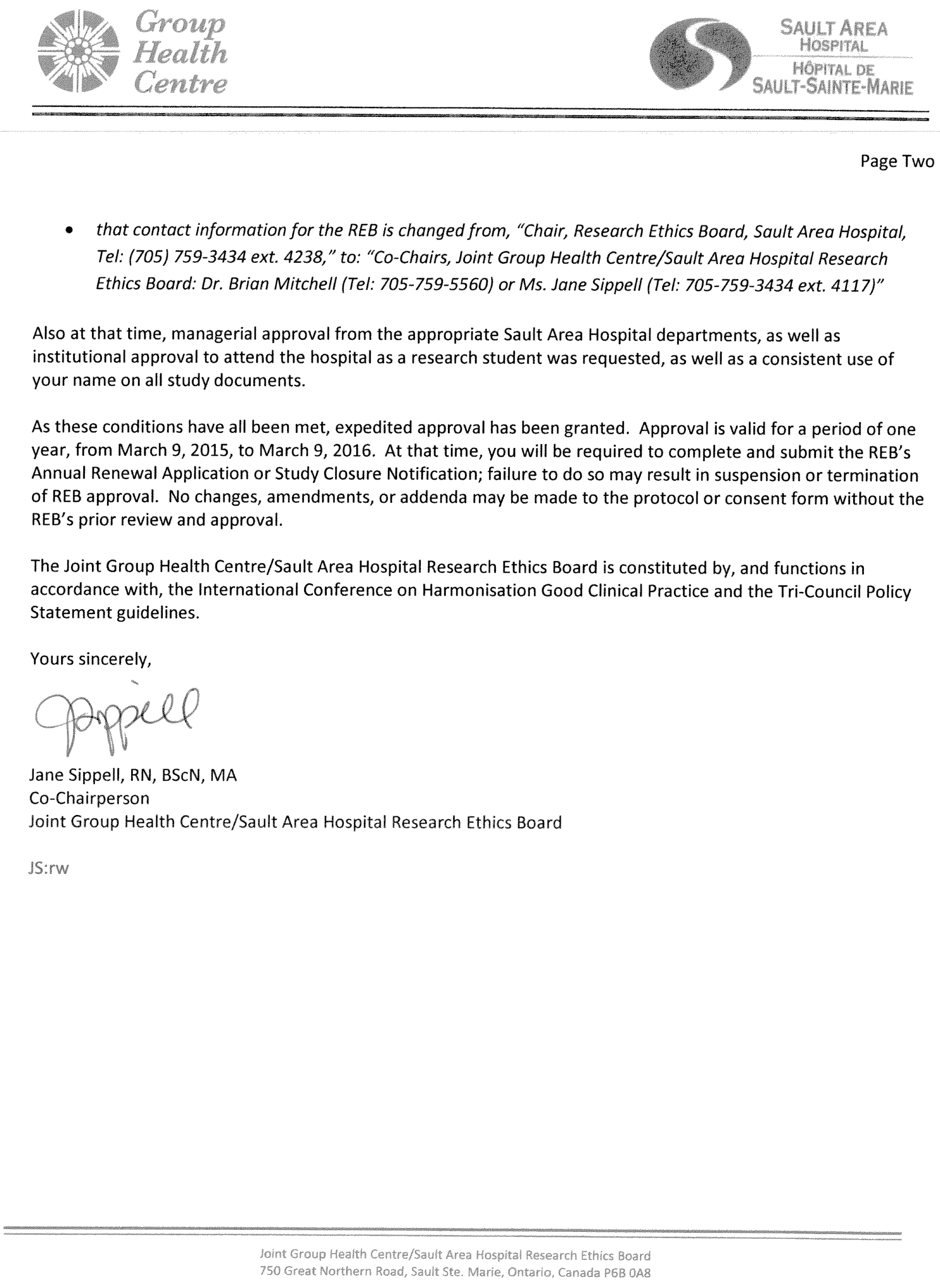


Group
Health
Centre

SAULT AREA
HOSPITAL
HÔPITAL DE
SAULT-SAINTE-MARIE

Page Two

- *that contact information for the REB is changed from, "Chair, Research Ethics Board, Sault Area Hospital, Tel: (705) 759-3434 ext. 4238," to: "Co-Chairs, Joint Group Health Centre/Sault Area Hospital Research Ethics Board: Dr. Brian Mitchell (Tel: 705-759-5560) or Ms. Jane Sippell (Tel: 705-759-3434 ext. 4117)"*

Also at that time, managerial approval from the appropriate Sault Area Hospital departments, as well as institutional approval to attend the hospital as a research student was requested, as well as a consistent use of your name on all study documents.

As these conditions have all been met, expedited approval has been granted. Approval is valid for a period of one year, from March 9, 2015, to March 9, 2016. At that time, you will be required to complete and submit the REB's Annual Renewal Application or Study Closure Notification; failure to do so may result in suspension or termination of REB approval. No changes, amendments, or addenda may be made to the protocol or consent form without the REB's prior review and approval.

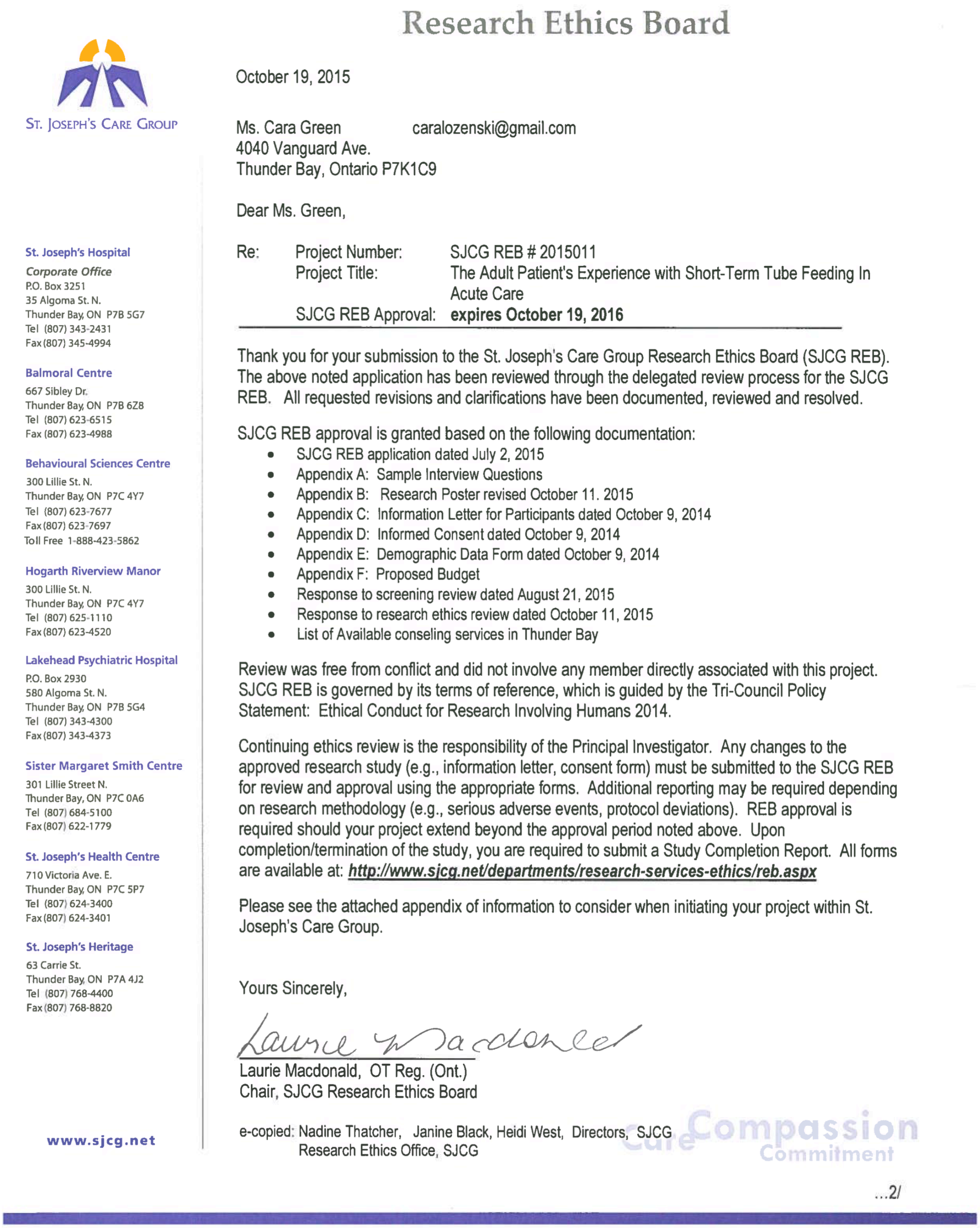
The Joint Group Health Centre/Sault Area Hospital Research Ethics Board is constituted by, and functions in accordance with, the International Conference on Harmonisation Good Clinical Practice and the Tri-Council Policy Statement guidelines.

Yours sincerely,

Jane Sippell, RN, BScN, MA
Co-Chairperson
Joint Group Health Centre/Sault Area Hospital Research Ethics Board

JS:rw

Appendix F: St. Joseph's Care Group Final Research Ethics Approval



Research Ethics Board

St. Joseph's Care Group

St. Joseph's Hospital
Corporate Office
P.O. Box 3251
35 Algoma St. N.
Thunder Bay, ON P7B 5G7
Tel (807) 343-2431
Fax (807) 345-4994

Balmoral Centre
667 Sibley Dr.
Thunder Bay, ON P7B 6Z8
Tel (807) 623-6515
Fax (807) 623-4988

Behavioural Sciences Centre
300 Lillie St. N.
Thunder Bay, ON P7C 4Y7
Tel (807) 623-7677
Fax (807) 623-7697
Toll Free 1-888-423-5862

Hogarth Riverview Manor
300 Lillie St. N.
Thunder Bay, ON P7C 4Y7
Tel (807) 625-1110
Fax (807) 623-4520

Lakehead Psychiatric Hospital
P.O. Box 2930
580 Algoma St. N.
Thunder Bay, ON P7B 5G4
Tel (807) 343-4300
Fax (807) 343-4373

Sister Margaret Smith Centre
301 Lillie Street N.
Thunder Bay, ON P7C 0A6
Tel (807) 684-5100
Fax (807) 622-1779

St. Joseph's Health Centre
710 Victoria Ave. E.
Thunder Bay, ON P7C 5P7
Tel (807) 624-3400
Fax (807) 624-3401

St. Joseph's Heritage
63 Carrie St.
Thunder Bay, ON P7A 4J2
Tel (807) 768-4400
Fax (807) 768-8820

www.sjcg.net

October 19, 2015

Ms. Cara Green caralozenski@gmail.com
4040 Vanguard Ave.
Thunder Bay, Ontario P7K1C9

Dear Ms. Green,

Re: Project Number: SJCG REB # 2015011
Project Title: The Adult Patient's Experience with Short-Term Tube Feeding In Acute Care
SJCG REB Approval: **expires October 19, 2016**

Thank you for your submission to the St. Joseph's Care Group Research Ethics Board (SJCG REB). The above noted application has been reviewed through the delegated review process for the SJCG REB. All requested revisions and clarifications have been documented, reviewed and resolved.

SJCG REB approval is granted based on the following documentation:

- SJCG REB application dated July 2, 2015
- Appendix A: Sample Interview Questions
- Appendix B: Research Poster revised October 11. 2015
- Appendix C: Information Letter for Participants dated October 9, 2014
- Appendix D: Informed Consent dated October 9, 2014
- Appendix E: Demographic Data Form dated October 9, 2014
- Appendix F: Proposed Budget
- Response to screening review dated August 21, 2015
- Response to research ethics review dated October 11, 2015
- List of Available conseling services in Thunder Bay

Review was free from conflict and did not involve any member directly associated with this project. SJCG REB is governed by its terms of reference, which is guided by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2014.

Continuing ethics review is the responsibility of the Principal Investigator. Any changes to the approved research study (e.g., information letter, consent form) must be submitted to the SJCG REB for review and approval using the appropriate forms. Additional reporting may be required depending on research methodology (e.g., serious adverse events, protocol deviations). REB approval is required should your project extend beyond the approval period noted above. Upon completion/termination of the study, you are required to submit a Study Completion Report. All forms are available at: ***http://www.sjcg.net/departments/research-services-ethics/reb.aspx***

Please see the attached appendix of information to consider when initiating your project within St. Joseph's Care Group.

Yours Sincerely,

Laurie W Macdonald

Laurie Macdonald, OT Reg. (Ont.)
Chair, SJCG Research Ethics Board

e-copied: Nadine Thatcher, Janine Black, Heidi West, Directors, SJCG
Research Ethics Office, SJCG

Care Compassion Commitment

...2/

Initiating Research Activity within St. Joseph's Care Group

If this project includes accompanying contracts or agreements to be signed by SJCG (e.g., industry-sponsored clinical trials, researchers' agreements) research activity **<u>must not</u>** begin until the contract has been executed.

Individuals accessing medical records or paper charts for the purposes of research are required to contact Information Systems and/or Health Records **<u>before</u>** accessing records. The Principal Investigator will be required to request access to files for research purposes for themselves and/or any member of his/her research team.

SJCG Information Systems contact information:
John Barro: <u>barroj@tbh.net</u> Tel: (807) 684-6402
SJCG Health Records contact information:
Vicki Polischuk: <u>polischv@tbh.net</u> Tel (807) 343-2454

<u>Description of Research Team</u>

Principal Investigator: Ms. Cara Green (Athabasca University graduate student)
4040 Vanguard Ave.
Thunder Bay, Ontario P7K1C9
caralozenski@gmail.com

Co-Investigator(s):

Best Contact for Project: same as Principal Investigator

Appendix G: Information Letter for Participants

Information Letter for Participants

The Patient's Experience Receiving Short-Term Tube Feeding in Acute Care

Principal Researcher:
Cara Green, BHEcol, RD
Master of Health Studies Student
Athabasca University
caralozenski@gmail.com
807-629-9467

Supervisor:
Dr. Virginia Vandall-Walker
Associate Professor
Faculty of Health Disciplines
Athabasca University
Athabasca, Alberta
Virginia@athabascau.ca
1-800-801-2572

Background

I am inviting you to be a part of a research study about how hospital patients experience tube feeding. I would like to recruit 6-12 patients for this study. I am a Registered Dietitian and a graduate student who has worked with people on tube feeding in the hospital for 12 years. I am not currently working in the hospital. I am doing this study as part of my Masters of Health Studies degree.

Purpose

The feelings experienced by patients while being tube fed are not well understood. The information and support desired by tube fed patients is also not well understood. In order to provide better care for tube fed patients, it is important for health care providers, such as dietitians, to have a good understanding of the experiences and needs of these patients. Only people experiencing tube feeding can provide this understanding. This study will help dietitians better understand and care for tube fed patients.

Study Procedures

If you decide to participate in this study, you will be asked to do one or two face-to-face interviews with me that may last about 30 to 60 minutes.

The first interview will occur in your hospital room (if you have a private room) or in a private meeting room close to your hospital room, or if you have been discharged, the interview will occur at a location of your choice or at your current health care facility. If you prefer, a family member may join the interview with you. The interview will begin with me answering any questions you have about this information form or the study. If you still desire to participate, I will then ask you to sign a consent form indicating your willingness to participate.

I will then ask you questions about
- your age
- your ethnic background
- the reason for your hospital admission and tube feeding
- the number of days you have been receiving tube feeding

- any food or drink you are eating by mouth
- the number of days you have been admitted to hospital
- your prior experience with tube feeding
- your contact information for a follow-up interview and/or to send you a copy of the results of the study
- any other details that you may wish to include.

The answers you and other participants provide to these questions will be combined into a table of data within my research report that will not identify you as an individual. This information provides a description of the people participating in the study that will help dietitians and other health care providers to better understand the study findings.

I will then ask you to share your story about your experience with tube feeding in the hospital. Throughout the interview, I may ask you questions that will help me understand your experience. Your story will be combined with the stories of other participants to determine common themes describing the experience of being on tube feeding. These themes will be reported as findings that will help dietitians and other health care providers to understand what tube feeding is like from the patient's perspective. Quotes from your story may be in the final report; however, the report will not contain any information that could identify you.

If there is a follow-up interview it will be face-to-face (if possible) at a location of your choice, several days later. If you have been discharged from the hospital to another health care facility, I will contact you in person about participating in a second interview. If you have been discharged home, I will only contact you about participating in a second interview if you agree, by telephone, email, or letter mail. If a face-to-face interview is not possible, we can talk on the telephone. During the follow-up interview I will discuss my study findings and ask you questions about those findings. The interviews will be digitally audio-recorded and used for this study only. All of the information you provide will be kept confidential and used for study analysis only.

Benefits to You
You are not guaranteed any direct benefits as a result of participating in this study. However, this study will provide information that may help others. The results of this study may be used to help Dietitians and other health care providers improve the care of patients receiving tube feeding in the hospital. Participation in this study will not result in any expenses to you other than the time spent for the interview(s). As a token of appreciation, a $5.00 gift card will be given following the interview.

Risks
It is unlikely that there are any risks to you being in this study. However, there is a chance that you may not feel comfortable sharing some of your experiences. If you find talking about your experience with tube feeding upsetting, with your approval, I can request counseling services within the hospital. If the interview takes place outside a hospital or health care institution, counseling services will have to be arranged at your discretion.

Voluntary Participation

Before you decide to participate, it is important that you know you do not have to take part in the study. Participation is voluntary and will not affect the care you receive in hospital. The staff of your nursing unit have been given information about this study and understand both that your participation is voluntary and that I cannot share your personal information or study findings with them. You may refuse to be in the study, and that is okay.

If you do participate, you can refuse to answer any questions you do not wish to answer. You may leave the study at any time before the analysis of information has begun. Even if you agree to be in the study you can change your mind and withdraw. If, before the analysis of your information has begun, you decide you do not want to be in the study, the information that you have provided will not be used in the study and it will be destroyed in a way that ensures your privacy and confidentiality.

Confidentiality
All of your personal information will be kept private. The only people who will have access to your data will be Dr. Virginia Vandall-Walker (my research supervisor), Ms. Colette Lebeuf (a professional transcriptionist) and myself. If you wish, you can choose or be given an alternate name for the purposes of this study to protect your identity. All written information about you will be kept in a locked filing cabinet in a locked office at Thunder Bay Regional Health Sciences Centre. All electronic data, which cannot identify you, will be password protected on a hospital computer and our personal computers with the files encrypted. Study data, including personal information about you will continue to be safely stored for five years after the study is over. During these five years, I may wish to use your data for further analysis for other studies, but your consent will be required before I can do so. After five years, all data from this study will be destroyed by shredding (paper data) or deletion (digital data).

Declaration of Conflict of Interest
I do not have any direct conflicts of interest, however I would like you to know that this research is being conducted to meet the requirements for my Masters program at Athabasca University, and is being funded in part, by a grant from Athabasca University. The findings of this research will contribute to greater knowledge about tube feeding. I plan to publish my findings in a research journal and present my findings to other professionals.

Participation and Further Information
I would very much appreciate your participation in this research project. I will return in a couple days to determine your interest in participating. If you are likely to be transferred to another facility I will request permission to visit you there, additionally, if you are discharged I will request permission to contact you or a family member or friend at home. Alternatively, you are welcome to contact me, Cara Green, directly by telephone at 807-629-9467 or email: caralozenski@gmail.com.

If you have any questions about this study before deciding to participate, please feel free to contact me, or my supervisor, Dr. Virginia Vandall-Walker at 1-800-801-2572 or email: Virginia@athabascau.ca.

Ethical Approval

The Athabasca University Research Ethics Board, Thunder Bay Regional Health Sciences Centre (TBRHSC) Research Ethics Board, and the St. Joseph's Care Group Research Ethics Boards have reviewed this study.

Should you have any concerns regarding your rights as a research participant or wish to speak to someone other than a research team member about this research project, you are welcome to contact:

Chair, Research Ethics Board
Thunder Bay Regional Health Sciences Centre
Phone: 807-684-6422
Email: ResearchEthics_Chair@tbh.net

Or

Chair, Research Ethics Board
St. Joseph's Care Group
589 N. Algoma St., Thunder Bay, Ontario P&B 5G4
phone: 807-346-3697 Toll Free (within Ontario and Manitoba) 1-855-239-8070
email contact for Chair: REB-Chair@tbh.net

Or

Athabasca University Office of Research Ethics
Phone: 1-800-788-9041, ext. 6718
Email: rebsec@athabascau.ca

Thank you very much for considering my request.

Sincerely,

Cara Green, BHEcol, RD
Master of Health Studies student
Principal Researcher,
Athabasca University
Tel: 807-629-9467
Email: caralozenski@gmail.com

Appendix H: Consent Form

Informed Consent

Title of Study: **The Patient's Experience With Short-Term Tube Feeding in Acute Care**

Investigator(s): **Cara Green, BHEcol, RD**
Faculty of Health Disciplines
Athabasca University,
Athabasca, AB
Phone: 1-807-629-9467

Virginia Vandall-Walker, PhD
Supervisor
Faculty of Nursing
Athabasca University,
Athabasca, AB
Phone: 1-800-801-2572

	Yes No
Do you understand that you have been asked to be in a research study?	______/_______
Have you read and received a copy of the attached Information Sheet?	_______/_______
Do you understand that during the interview what you say will be digitally recorded?	______/_______
Do you understand that you may be asked to participate in a second interview even if you are discharged from hospital?	______/_______
Do you understand the benefits and risks involved in taking part in this research study?	______/_______
Have you had an opportunity to ask questions and discuss this study?	______/_______
Do you understand that you are free to leave the study at any time, without having to give a reason?	_______/_______
Has the issue of confidentiality been explained to you?	_______/_______
Do you understand who will have access to your records, including personally identifiable information?	_______/_______

Athabasca University

This study was explained to me by: ______________________________
Name of Person

I agree to take part in this study: ______________________________
Signature of Research Participant

Date: ____________________

____
Name

____
Signature of Witness

Date: ______________________

____
Printed Name

I believe the person signing this form understands what is involved in the study and voluntarily agrees to participate.

____
Signature of Investigator

Date: ______________________

Athabasca University

Appendix I: Demographic Data Form

October 9th, 2014

Demographic Data Form

Title of project: The Patient's Experience With Short-Term Tube Feeding in Acute Care

Pseudonym ______________ Date of Interview ___________________

Personal Information

Initials: ____

Address: ____

Phone Number/Email: _______________________________

Age: _____ Gender: _____

Cultural background: __________

Education level achieved:______________

Diagnosis this admission: ____________

Indication for tube feeding (if different than above diagnosis): ____________

Number of days on tube feeding: _________________

Eating or drinking food and liquids by mouth: yes / no

If yes: what food and liquids? ______________

How long on oral intake? ________________

How many days in hospital: first interview: _______ second interview:_______

Previous experience with TF: Yes /No

If yes: NG / PEG / Hospital /home? ______________

Would you consent to a second interview? Yes/No

If yes, and you are discharged from the hospital, how would you like me to contact you?

Phone____, Email____, or Mailing Address____

Would you like a copy of my research report sent to you once the study is completed? Yes/No

Additional Notes ____

Appendix J: Sample Interview Questions

Interview Questions

1. How would you describe your experience with tube feeding while in the hospital?
    a. What was that like for you?
2. How did tube feeding affect you (e.g. psychologically: relief, fear, or, physically: satiety, discomfort, pain, nausea, diarrhea, bloating, blockage)?
3. What was the main advantage of being on TF?
4. What was the main disadvantage of being on TF?
5. How worthwhile has TF been to you?
6. Were you provided with information about tube feeding and what to expect with this therapy?
    a. What other information about tube feeding would you have liked?
7. How would you describe the support you and your family received from the health care providers (e.g. Dietitian, nurse, physician)?
    a. Is there any other support you and your family would have liked to have received while on TF?
8. How would you describe the support of your family members?
    a. What could they have done differently to support you while on TF?
9. How would you describe the experience of being unable to eat?
    a. What was that like for you?

Appendix K: Sample Interview Questions (Additional)

Additional Interview Questions

1. How do you feel about the length of time you will be on tube feeding?
2. How is information helpful (does it provide comfort, relief, stability, enable mental preparation?)
3. How would your experience with TF been different had you been given more information?
4. Does it matter who gives you the information, i.e. RN or RD?
5. How would you describe the adequacy of the information provided to you by the Dietitian, Nurse, Physician?
6. Explain how your Dietitian, Nurse, Physicians supported you or didn't support you, what did that look like?
7. What information did the Dietitian, Nurse, Physician provide to you with respect to resuming eating and drinking?
8. How could the Dietitian have been more helpful?
9. What do you perceive is the Dietitian's role on the health care team?
10. Who would you prefer develop and troubleshoot any problems your tube feeding regime?
11. When a health professional comes in to help you, would you mind them holding your hand? Why/why not?
12. How does the support of family and friends affect your tube feeding experience?
13. Is there anything else that could have been done to support you while on tube feeding?
14. What actions could have alleviated your discomfort with TF/being unable to eat?
15. Can you describe why being unable to eat and drink was so difficult?
16. How has eating/drinking changed since starting TF?
17. What do you think was the purpose of TF?
18. What do you think TF did for you?
19. Did anyone ask you what you wanted with TF, i.e. your care goals?
    a. What are your goals?
20. How are you/did you cope with TF?
21. What are some of the factors that enabled you to cope?
22. What about YOU helped you to get through this experience?
23. Do you think some types of people would have a harder time than others dealing with TF? Why/why not?
24. What characteristics would help you or anyone, dealing with TF?