

HOME PARENTERAL NUTRITION AND THE INDIVIDUAL AND FAMILY
SELF-MANAGEMENT THEORY

By

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for the degree of Doctor of Philosophy

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Dedication

This work is dedicated to my parents, Booker, (though no longer here with us), and Annie Payne who encouraged me to further my education right from the beginning! To my husband, Edward and daughters, Alicia and Anna and family – I am thankful for your love and appreciate your support of my career. I would also like to thank my extended family, particularly, Erma and Ilona. I am grateful for your love and that you stood in the gap for me – your efforts are sincerely appreciated. Thank you *Lord*, for providing me the courage to complete this work and for your unwavering guidance.

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Home Parenteral Nutrition and the Individual and Family
Self-management Theory

Abstract

By

BETTY NAPOLEON

Parenteral nutrition (PN) is an intravenous infusion that is a vital nutrient source for an increasing number of individuals that is more commonly being administered in the home. Patients on home PN, their families and the interdisciplinary health care team, must collaborate to achieve optimal patient outcomes. Prior research on individual and family self-management and health outcomes of persons on home PN is lacking.

Purpose and Theoretical framework: The Individual and Family Self-Management Theory (IFSMT) (Ryan and Sawin, 2009, 2014) comprised of the context (physical illness and impairments), process (health behaviors) and proximal and distal outcome dimensions. The relationships among the study variables of these dimensions were explored.

Design: Exploratory, descriptive, retrospective analysis of an existing database. The Home Total Parenteral Nutrition database, electronic health record, educational reports and Health Professional Shortage Area Index were examined.

Subjects: Adults new to home parenteral nutrition therapy in 2013, on PN therapy for 30 days or longer, and managed by the nutrition support teams were included in the sample. Those excluded required PN therapy for less than 30 days, were

prescribed home IV fluids only, had previously received PN or were admitted to long-term care.

Data analysis: Descriptive, chi-square and multiple and logistic regression statistics were used to address the research questions.

Results: There were significant relationships between context variables: gender, females were 2.5 times more likely to be fully engaged; non-rural subjects were 4.7 times more likely to be fully engaged; subjects with short bowel syndrome (SBS)/malabsorption were 5 times more likely to be fully engaged as compared to those with obstruction/ileus. For every additional day on home PN therapy, the odds for being fully engaged in care increased by one percent. There were no significant relationships noted among context and proximal outcome variables and acute care readmission, or between the educational model and engagement in care.

Conclusion: Due to the exploratory nature of this study, replication, with a larger sample is recommended. This examination provided insight into the relationships among the context and process variables of the model and engagement in care and acute care readmission.

Chapter 1

Purpose

The purpose of this exploratory, descriptive retrospective analysis of an existing data set was to examine the Individual and Family Self-Management Theory (IFSMT) and the relationships among the context and process factors and proximal and distal outcomes among adults on home parenteral nutrition (PN) and their families. This chapter addresses the problem, background, significance of the study and the relevance to the nursing profession. In addition, the theoretical framework, constructs, concepts and the definition of terms are described.

Problem

Parenteral nutrition (PN) is intravenous feeding of nutrients which may include protein, carbohydrate, fat, minerals and electrolytes, vitamins and other trace elements through a central line [American Society for Parenteral and Enteral Nutrition (ASPEN), 2012]. It is administered to those who have intestinal failure and are unable to eat or absorb adequate food intake enterally to maintain their nutritional status (ASPEN, 2012; Dreesen et al. 2012; Kirby, Corrigan, Speerhas & Emery, 2012). The Agency for Healthcare Research and Quality (AHRQ) estimates that in 2012, there were approximately 318,000 hospital discharges of persons with PN. The average number of PN discharges for the years 2009 – 2011 was 337,000 (AHRQ, 2015). The precise number of adult discharges was not listed, however, Mirtallo (2012) reported that in 2009, about one-third of those discharged from hospitals with PN, were newborns and children. Current initiatives including the “Sustain” registry introduced by ASPEN in 2010, are underway to gain more information about the exact numbers, demographics

and outcomes of patients using this therapy nationwide in order to better inform the science. The registry also provides a benchmarking tool for subscribing institutions to measure against aggregate data (ASPEN, 2013). Parenteral and enteral nutrition therapies are listed among the top six procedures experiencing the most rapid growth according to AHRQ (2011) and with the ongoing transition to shorter hospital stays, more medical and nutritional care will be provided at home.

Patients are being discharged from acute hospital settings earlier with more complex care needs. Many persons have conditions that will require ongoing care for weeks or months at time and because of the chronic nature of their illnesses, they are choosing to manage that care when feasible, in the home with assistance.

Virginia Henderson (1985), a nursing researcher, theorist and visionary made note of the fact that “high technology” care was occurring not only in intensive care units but also in the home. “Individuals and families are electing home rather than hospital care. Relatives or friends, taught and helped by nurses or technicians employed by the manufacturers of medical equipment, are providing home care for persons who require parenteral feeding, dressing and drainage of wounds, inhalation therapy, and comparable procedures” (Henderson, 1985, p. 2). Furthermore, she comments that differences in the environments of care are minimized as home care nurses and patients become proficient in the use of this technology in the home (Henderson, 1985).

Home parenteral nutrition therapy is necessary for the individuals for whom it is prescribed. It involves complex chronic care and requires that individuals and their caregivers gain specific knowledge and implement technology-based procedures and in most cases, adherence to a daily care regimen (Baxter, Fayers & McKinlay, 2005).

Nutrition support teams, health care providers and home care personnel have a major responsibility for educating patients and their families regarding safe PN management. PN is also very costly. Thus patients and their families bear the burden of the expenses along with the insurance providers.

Individual Financial Considerations

Costly hospital stays along with improvements in technologies available in the home are major reasons why PN is increasingly provided outside of the acute care setting (Piamjariyakul, Ross, Yadrach, Williams, Howard & Smith, 2010). Case managers and social workers have a responsibility to confirm that there is a payer source prior to discharge and the initiation of home PN due to known expenses associated with this therapy (Hendrickson & Corrigan, 2013). It is reported that most individuals with commercial insurance, Medicare or Medicaid, are not guaranteed complete coverage for the care, equipment and supplies required for this therapy and a substantial cost burden has been documented particularly with long-term therapy (Piamjariyakul et al., 2010). Kelly (2006) states, “The cost of home nutrition support, particularly PN, is one that few, if any, of us could personally bear for the long term” (p. 539). In 2006, Kelly estimated that costs for the home PN solution alone ranged from \$270 to \$409 daily dependent on the formulation of the solution administered, with an additional \$45 daily for pump rental and supplies.

Twenty-five percent of all new home PN patient costs are covered by Medicare and that increases to 60% for persons requiring long-term PN therapy (Howard, 2006). Home PN equipment and supplies are billed under Medicare part B prosthetic coverage and sometimes part D if diagnostic criteria are met. Medicare has very specific

diagnosis requirements for coverage of home PN with two primary qualifications being physician documentation of a permanent condition requiring at least 90 days of therapy and inability to maintain weight by other means such as pharmacological treatment or enteral feedings (Hendrickson & Corrigan, 2013). In 2009, Medicare part B and D expenditures for home parenteral nutrition averaged about \$33,511 per person or \$159,000,000 - the largest expenditure for any home infusion therapy (Medicare Payment Advisory Commission, 2012). Even with Medicare spending at this level, individuals still have a 20% copay after the initial 20 days which adds additional charges of up to \$75 per day, but persons with secondary insurance have found that these costs may be covered at least for a time (Hendrickson & Corrigan, 2013; Kelly, 2006). Pumps that are used for PN infusion are covered for up to 13 months by Medicare, thereafter, pump rental will be the responsibility of the secondary insurer or the individual in the absence of that coverage (Hendrickson & Corrigan, 2013).

In today's economic environment, it is not uncommon to have patients without health insurance coverage of any type which presents an exceedingly difficult challenge. Charity care programs including agency-based options have also given individuals needed financial assistance or attempted to defray or reduce patient costs related to this life-sustaining therapy. When these options fail, acute care institutions bear PN therapy expenses via extended inpatient stays until other payer sources can be obtained.

Because of the chronic and complex care that is accompanied by tremendous personal and caregiver responsibility and use of personal and financial resources, issues with accessibility and use of nutrition support teams as well as the increase in frequency of

PN being managed in the home, it is important to examine factors that may impact health outcomes of these individuals. Researchers have examined the impact on caregivers assisting family members with PN (e.g. Smith, 1994; Smith, 1999; Smith et al., 2002; Smith, Giefer & Bieker, 1991), problems and complications (e.g. Huisman-de Waal et al., 2011; Konrad, Corrigan, Hamilton, Steiger & Kirby, 2012; Persoon et al., 2005; Smith et al., 2003), financial and insurance considerations (e.g. Howard, 2006; Kelly, 2006; Piamjariyakul et al., 2010), and quality of life (Baxter, Fayers & McKinlay, 2005; Howard, 2002; Howard, 2006; Huisman-de Wall, Schoonhoven, Jansen, Wanten & van Achterberg, 2006; Winkler, 2005; Winkler et al., 2010). However, literature using the individual and family self-management model with home PN patients was not found and the relationships among the context, process and outcome factors pertinent to this population warrants further exploration.

Background

Malnutrition

Primary indicators for initiation of parenteral nutrition in adults is malnutrition and chronic illness. Individuals with chronic conditions, such as Crohn's disease or ulcerative colitis that require short or long-term parenteral nutrition therapy are usually malnourished. White, Guenter, Jensen, Malone & Schofield (2012) define adult malnutrition by utilizing three etiology-based categories. The first category is starvation-related malnutrition, which is pure, chronic starvation as seen in anorexia nervosa. The second category is chronic disease –related malnutrition (lasting three months or longer) resulting, for example, from organ failure, pancreatic cancer and rheumatoid arthritis. Lastly, acute disease or

injury-related malnutrition that occurs after major infection, trauma, burns or closed head injury is the third category described. PN is sometimes initiated for acute conditions when resolution is anticipated within several weeks or months as is the case with post-operative ileus or fistulas.

White et al., 2012 also recommended six evidence-based metrics or characteristics to guide the diagnosis of malnutrition suggesting that the presence of two or more would be indicative of the condition:

- Insufficient energy intake
- Weight loss
- Loss of muscle mass
- Loss of subcutaneous fat
- Localized or generalized fluid accumulation that may sometimes mask weight loss and,
- Diminished functional status as measured by handgrip strength

(p. 277)

Malnutrition is a consequence and a complication of intestinal failure and is often the reason that PN is prescribed. Parenteral nutrition and the diseases or conditions with the highest prevalence for use of the therapy are discussed next.

Parenteral Nutrition

Howard (2006) examined the outcomes of individuals on home PN in North America and Europe. She found the most frequent diagnoses of individuals who were receiving PN included: cancer; Crohn's disease; ischemic bowel; motility disorder; acquired immune deficiency syndrome; congenital bowel; and radiation enteritis.

Persons who experienced these diagnoses ranged in age from infancy through older adulthood (Howard, 2006). In addition to these diagnoses, Kirby et al. (2012) added short bowel syndrome, severe pancreatitis refractory to enteral nutrition trial, high-

output gastrointestinal or pancreatic fistulae, bowel ischemia, bowel obstruction and inflammatory bowel disease (which includes Crohn's disease) with malabsorption as other indications for parenteral nutrition.

DeChicco & Steiger (2000) divide conditions resulting in intestinal failure into two categories. The first category is "Nonfunctional GI tract" and includes severe diarrhea and malabsorption, short bowel syndrome, intractable nausea/vomiting or bowel obstruction or ileus. The second category is "Need for Bowel Rest" and includes: severe pancreatitis, enterocutaneous fistula or exacerbation of Crohn's disease or ulcerative colitis.

Despite being a complex therapy, PN has been administered successfully in acute care settings since 1966 (Dudrick, 2002; Dudrick, Wilmore, Steiger, Mackie & Fitts, 1970) and in homes in the United States since 1968. PN use, however, is not without risk of serious complications including catheter-related blood stream infection (CRBSI), fluid and electrolyte abnormalities, metabolic bone disease and intestinal failure-associated liver disease (De Burgoa, Seidner, Hamilton, Stafford & Steiger, 2004; Kirby, Corrigan, Speerhas & Emery, 2012; Muscaritoli, Molino, Laviano, Rasio & Fanelli, 2012; Putchakayala et al., 2009; Shatnawei et al., 2010). Every practitioner evaluating an individual for this therapy must weigh the advantages against the potential adverse responses prior to initiating treatment. As Steiger (2007) so aptly states, "The only disease that parenteral nutrition can possibly cure or prevent is malnutrition while providing time for the application of other medical or surgical therapies in patients who have lost gastrointestinal tract function" (p. 591).

Parenteral nutrition and cancer

The use of parental nutrition in cancer patients, though common, is sometimes controversial due to the lack of clear evidence that outcomes are improved in this population and benefits, potential adverse responses and costs must be evaluated before proceeding with this option. (DeChicco & Steiger, 2000; Marian & Roberts, 2010). Malnutrition in cancer patients may occur acutely or chronically because of disease or treatment-related malfunctioning of the gastrointestinal tract, thus it becomes an indication for the use of parenteral nutrition (Marian & August, 2013). Parenteral nutrition can help sustain these patients nutritionally during curative or palliative therapy at a time when they are unable to meet their needs by use of the gastrointestinal tract (Marian & Roberts, 2010). Cancer cachexia symptoms – anorexia, fatigue, inadequate nutrient and energy intake, weight loss and wasting of muscle and fat mass that are refractory to treatment, are not reversed by nutritional support (Fearon et al., 2011; Marian & Roberts, 2010; Marian & August, 2013). Literature seems to support PN use in higher functioning individuals who have less debility and in those who need supplementation along the disease trajectory. Additional research is indicated in regard to the issue of parenteral therapy use in individuals with cancer.

Parenteral nutrition, Crohn's disease and Short bowel syndrome

Crohn's disease is an autoimmune inflammatory bowel condition that can cause thickening of all layers of the mucosa of the entire gastrointestinal tract although it most commonly affects the ileum of the small intestine and the ascending colon (Crohn's and Colitis Foundation of America, 2013). Individuals from ages fifteen to thirty-five years are primarily affected by this condition. (Crohn's and Colitis Foundation of America,

2013). When Crohn's related changes occur in the gastrointestinal tract, parenteral nutrition may be the treatment option of choice for acute or more complicated manifestations when enteral feeding is not possible. Persons with Crohn's disease were reported by Howard (2006) to have survived longer than those with other primary diagnoses.

Short bowel syndrome may occur as a complication of Crohn's disease, congenital bowel or ulcerative colitis, for example, when a person has undergone surgical resection of diseased, non-functioning small intestine and is left with a GI tract that is less than 200 cm in length as a result (Parekh & Steiger, 2007). In addition, intestinal ischemia, radiation enteritis, volvulus or cancer can also contribute to the development of short bowel syndrome leaving the person with severe malabsorption that presents as diarrhea, dehydration, electrolyte abnormalities and malnutrition (Parekh, Seidner, Steiger, 2005). "Patients with difficulty ingesting enough nutrients and fluids for weight maintenance and fluid balance may benefit from nocturnal enteral nutrition and hydration. Those with inadequate absorptive capacity despite maximization of oral and enteral intake will need parenteral nutrition or hydration" (Parekh & Steiger, 2007, p. 10). Parenteral nutrition may be required on a short-term or life-long basis for those with short bowel syndrome and the decision to initiate PN will depend on how much intestine remains and how severe the malabsorption as related to fluid, nutrient and electrolyte status.

Parenteral nutrition in other populations

According to the Centers for Disease Control (CDC) in 2010, 1.1 million people were living with human immunodeficiency virus (HIV) and of those, about 16% do not

know they are infected. Parenteral nutrition is considered an option for nutritionally deficient persons with HIV or acquired immunodeficiency syndrome (AIDS). Coyne-Meyers & Trombley (2004) conducted an extensive review of the literature on the nutrition management in (HIV) infection in the era prior to the use of highly active antiretroviral therapy (HAART) and since its inception. The researchers summarized that improvements in weight, nutritional markers and quality of life with the use of parenteral nutrition were reported in the literature and they emphasize that benefits versus the potential for adverse reactions should be carefully assessed with patient input on a case by case basis (Coyne-Meyers & Trombley, 2004).

Gasparis & Tassiopoulos (2001) discussed nutritional support in the patient with HIV infection and state that parenteral nutrition should be considered when enteral nutrition is not feasible. They believe that PN effectiveness depends on the person's overall clinical situation. Wasting is still seen in this population and the timing of access to healthcare services impacts the health outcomes.

Patients with high output gastrointestinal fistulae, bowel ischemia, motility disorders and those with malabsorption issues are also candidates for parenteral nutrition therapy due to the deleterious impact that these conditions have their nutritional status (Kirby et al., 2012).

Financial considerations and home care

The Centers for Medicare and Medicaid (CMS) have indicated that funding for services provided to long-term care facilities and for home care services is expected to increase in the coming years. A 59% growth in skilled nursing facility expenditures is projected, but home care service expenditures is expected to double by 2021 with

Medicare and Medicaid remaining the primary payers of benefits for services (CMS, 2011). In 2010 expenditures including out-of-pocket costs for hospital care were \$814 billion, skilled nursing care were \$143 billion and \$70 billion were spent for home care services. The National Association for Home care and Hospice (2010) reported that an estimated 12 million people received home or hospice care for reasons such as acute illness, long-term health conditions, permanent disability and terminal illness.

Commercial and governmental insurers expect that care will be provided in the home whenever it is safely possible as a way of trimming healthcare costs. In their 2011 “Positioning Statement” on the condition of the home care industry entitled, “Home - the best place for health care”, the Joint Commission supported the provision of care in the home because it is less costly and home care interventions can reduce hospitalizations and improve quality of care for those with chronic conditions or who are experiencing adversities (Joint Commission, 2011).

With the implementation of the Affordable Care Act in 2014, overall health spending is anticipated to increase approximately 7.4 percent and fewer persons will be uninsured, however, out-of pocket expenditures are expected to decline (CMS, 2011). It is currently unknown how the Affordable Care act will impact commercial insurers, Medicare and Medicaid with regard to home parenteral nutrition costs, payment and reimbursement. Several models such as the Patient-centered medical home and the “Guided Care” model are being implemented however, in junction with Accountable Care Organizations to help control costs and provide more patient-focused effective care and improve outcomes. [Boult, Karm & Groves, 2008; Commission for Case Management Certification, (CCMC) 2011].

Factors in Self-management of home PN

Complex Chronic Care

Home PN therapy involves patient and caregiver commitment to a rigorous and complex daily care regimen (Winkler, Ross, Piamjariyakul, Gajewski & Smith, 2006). Stringent schedules, symptom management, and the need to make complicated clinical decisions may occur frequently for these individuals and their caregivers leaving minimal time for usual routines and tasks (Smith, 1999). Technology must be utilized in order to complete the necessary care and individuals and their families will have these responsibilities as long as the indication for PN exists.

Family and Caregiver support

In spite of the complexity of care, persons requiring parenteral nutrition are among those with increasing frequency, who are choosing to receive nutritional support therapy at home. Researchers have reported that families willingly assist with this care even though the technology and equipment may be anxiety-provoking initially. Family caregivers in a study conducted by Smith, Giefer & Bieker (1991) reported the overall experience as gratifying and were thankful the technology facilitated care in the home. Smith's (1994) study built on previous research and utilized the "Caregiver effectiveness model" and found, "The reciprocal benefits the caregivers perceived and the caregivers' empathic-concern motivation to help appeared to enhance their own as well as the patient's quality of life" (Smith, 1994, p. 37).

Nutrition Support Teams

Both ASPEN and the European Society for Clinical Nutrition and Metabolism (ESPEN) recommend that the parenteral nutrition therapy is managed by interdisciplinary Nutrition support teams (NST) with specialized nutritional training typically comprised of physicians, dietitians, pharmacists and nurses (Ross & Smith, 2011; Schneider, 2006; Staun et al., 2009). The NST conducts nutrition assessments, determines needs, provides nutrition recommendations and manages nutrition support therapy (DeLegge & Kelly, 2013).

Schneider's (2006) review of the literature on nutrition support teams found that patient safety and outcomes improved and strong financial benefits were noted for healthcare institutions in the studies examined as compared to those managed by independent practitioners.

Interdisciplinary nutrition support teams along with the creation and implementation of evidence-based standardized clinical care guidelines were proven to have a positive impact on nutrition outcomes.

Nutrition support teams began in the early 1970's (Guenter et al., 2004) and by the 1990's there were approximately 550 nutrition support teams functioning in about ten percent of hospitals nationwide, but funding changes along with initiation of "diagnosis related groups" (DRGs) limited the hospital's capacity to bill for NST services thus, the number of teams has declined (Bistrain, 2009). DeLegge and Kelly (2013) reported that in 2008 only 42% of ASPEN survey respondents reported a formal NST was in place in their practice setting with the majority reporting from hospitals. In the current healthcare financial environment, funding remains limited and a concern.

As a consequence, some individuals requiring PN may have to travel great distances to

hospitals with nutrition support teams or with specially trained nutrition health care providers for PN initiation and management.

Accessibility and Potential Barriers

Home management of PN is an ongoing expectation for individuals and their caregivers due to the current post-acute care environment. Discharge planners aim to place home PN patients with long-term needs in capable institutions or with home care agencies that can assist with provision of safe and effective care, however, many skilled nursing facilities (SNFs) and home health care (HHC) agencies are unable to accommodate these patients due either to cost/reimbursement issues, or lack of staff proficient in PN care requirements. This is consistent with what Howard (2006) reported regarding long-term care of those requiring long-term therapy.

Patients from rural areas present an even greater challenge because there may not be an accepting facility or agency in their region at all. The patient and family have no option other than to learn and manage home PN under these circumstances. Nutrition support teams seek area or regional support for these individuals especially with new initiation of care so that health outcomes are not compromised.

Significance of the Study

Parenteral nutrition therapy is being administered in increasing numbers and the home environment is a setting where many individuals and their families are choosing to provide the care. PN care requires specialized knowledge and training of the individuals and those involved in care managing. The literature supports that problems and complications are more likely when individuals and families are not properly instructed, when nutrition support teams are not managing care or utilizing evidence-

based guidelines, and if a patient does not have a supportive environment or belong to a peer-support organization. Individuals requiring PN sometimes live in areas where accessibility to hospitals, home care agencies and skilled nursing facilities that are familiar or proficient in the care and management of the conditions necessitating use of PN may be quite limited thus necessitating travel to institutions that are capable of addressing these needs. Nurses and other healthcare providers seeking to facilitate arrangements for ongoing care management for these individuals and their families are met with many challenges.

The examination of personal characteristics, accessibility and other factors critical to parenteral nutrition therapy merits further exploration. There is some substantiation of positive differences in individuals managed by nutrition support teams as compared to those cared for by individual practitioners (Schneider, 2006). Are there differences in health outcomes for those who have limited accessibility to specially trained nutrition teams? Are these individuals able over time to form alliances with local providers who are willing to become proficient in their care or do they retain management with the hospital where PN was initiated? Are there relationships between PN duration, social support, age and incidence of readmission?

The care of persons requiring parenteral nutrition is an important area of inquiry for nurses because of the current and projected growth in the use of this therapy (AHRQ, 2011). Secondly, PN management is known to be interdisciplinary and nurses have a major responsibility in teaching, monitoring, guiding and supporting in homes and at bedside throughout the care continuum. Caring for human beings within their environments to maximize adequate nutrition is central to the discipline of nursing.

Nurse theorists, researchers and scholars have discussed at length the elements thought to comprise the essence of nursing. Fawcett described the nursing metaparadigm as consisting of the concepts of person, health, environment and nurse (1984) and modified person to human beings in 2005 (Fawcett, 2013). Schlotfeldt (1987) believed that the human-health-seeking perspective should be the focus of the definition of nursing. She stated that, “Nursing is the appraisal and the enhancement of the health status, health assets and health potentials of human beings” (Schlotfeldt, p. 67). Donaldson & Crowley (1978) believe that nursing has art and science aspects and Donaldson (2002) felt it imperative that nursing be clearly defined to increase visibility so that other scientists understood the profession. She defined nursing science as, “The science of personal and familial human health ecology” (p. 61).

Ecology is the science that explores organism patterns of interaction and interrelationships within their environments (Donaldson, 2002). Newman, Sime & Corcoran-Perry (1991) state that, “Nursing is the study of caring in the human health experience” (p. 3). They believe that the concepts of caring and human health experience are included in the focus of nursing’s body of knowledge. The focus of this study is on human nutrition, which is fundamental to an individual’s health and well-being. Nurses have a critical role in supporting adequate nutritional intake regardless of how it is provided.

Nutrition support nursing has evolved over time with nurses working as direct care providers, educators, consultants, researchers and administrators (Guenter, Curtas, Murphy & Orr, 2004). Nutrition support nurse case managers have an expanding role in managing costs and resource utilization due to shifting fiscal and regulatory priorities

(Daniels & Tahan, 2014). Among their many responsibilities, case managers facilitate discharge planning, care transition, and financial and insurance matters and are indispensable in today's economic climate (CCMC, 2012; Daniels & Ramey, 2006). Furthermore, coordination of the interdisciplinary services necessary for effective management of home PN is a prime responsibility and is essential for high quality, safe care in the home. The Standards of Practice of nutrition support nursing reflect the elements of the nursing metaparadigm. This specialty focuses on prevention of nutrition-related illness and injury and seeks to optimize nutrition health and alleviation of suffering while advocating for individuals, families, communities and populations with nutritional deficits (ASPEN, 2007).

The execution of effective PN in the home necessitates the involvement of multiple disciplines and much of the literature examining the issues and problems of this population is interdisciplinary – offering the perspectives singularly or conjointly of nurses, physicians, nutritionists and pharmacists as well as other professionals. The discipline of nursing contributes to and benefits from this knowledge as nurses care for persons needing PN from infancy to older adulthood must be engaged in building the science of parenteral nutrition management.

Theoretical Framework

The literature is replete with evidence of improved health outcomes in individuals with chronic conditions integrating self-management behaviors, but literature was not found that addressed self-management in the parenteral nutrition population. Family and caregiver assistance is crucial to effective care of individuals managing chronic conditions and numerous scientists have provided empirical evidence

in support of this. However, studies that examined both self-management and family management behaviors and outcomes of adults on home parenteral nutrition within the context of the Individual and Family Self-management theory model were not found in the literature.

Ryan and Sawin's (2009) Individual and Family Self-Management Theory (IFSMT) is an appropriate descriptive middle-range model to guide the science on the care experience of the adults with home PN and shares some of the same concepts as the Grey, Knafl & McCorkle model (2006). The theory is a culmination of extensive research and the result of a collaboration of the two researchers. It builds on prior self-management research with theoretical underpinnings in systems theory, the Integrated Theory of Health Behavior Change (Ryan, 2009; Ryan, Pumilia, Henak & Chang, 2009), and the Ecological Model of Secondary Conditions and Adaptation (Sawin, Bellin, Roux, Buran & Brei, 2009; Sawin, Cox & Metzfer, 2004).

Ryan and Sawin (2009) posit that, "Self-management is a multidimensional, complex phenomenon that can be conceptualized as affecting individuals, dyads, or families across all developmental stages" (p.222). These theorists emphasize that IFSMT has the inclusion of a "purposeful incorporation of health-related behaviors into an individual's or family's daily functioning" (p. 222). Ryan and Sawin (2009) believe that simultaneous use of both the individual and family lens is more comprehensive and it improves outcomes when both perspectives and that of the broader community are considered.

Self-management is described in the literature as three distinct phenomena – a process, a program and as outcome (Ryan & Sawin, 2009). The theorists believe that

self-management is broader than self-care, the completion of activities of daily living, and the provision of patient education. Ryan and Sawin emphasize that self-management should facilitate skill development, health behavior change and acceptance of responsibility for chronic illness management (Ryan & Sawin, 2009).

The theory has three dimensions: context, process and outcomes, which all have subdivisions and add further clarity to the model. The context dimension consists of risk and protective factors with three main components. The first component is condition-specific factors which address treatment and condition complexity along the trajectory; Physical and social environment elements include access to care, transportation, social capital, culture, setting and provider transitions is the second component. The third component focuses on individual and family characteristics such as literacy, information processing capabilities, perspectives and developmental stages. Context factors will be examined as they are of particular interest with PN population because of the inclusion of the concept of complexity and because of key elements, specifically access to care.

The process dimension is comprised of the broad categories of: knowledge and beliefs, self-regulation and skills and abilities; and, social facilitation. This dimension includes self-factors some of which are: self-efficacy, goal setting, self-monitoring, reflective thinking, decision making, influence and collaboration. From the perspective of parenteral nutrition therapy, the process dimension refers to individual and family knowledge and understanding of care requirements, self-efficacy, and skill attainment of the multiplicity of care regimens.

The outcome dimension is comprised of the proximal and distal factors. Proximal outcomes are more immediate such as engagement in the care and treatment regimen and management of symptoms. In addition, organization and completion of daily tasks, scheduling of in-home and outpatient health provider visits, and timing of supply and equipment deliveries are indicative of individual and family self-management behaviors of the proximal outcome dimension.

For those on parenteral nutrition, barriers such as cost factors, insurance deficits and loss of social support have the potential to adversely affect outcomes. Distal outcomes are more long-range. Health status, stabilization, quality of life or well-being, worsening of the condition or illness which may lead to readmission are possible examples of distal outcomes. The ultimate outcome for individuals administering parenteral nutrition is that malnutrition or the causative factors that led to the initiation of the therapy would be resolved. Maintaining a perceived acceptable quality of life might be a distal outcome for those for whom PN becomes a life-long therapy.

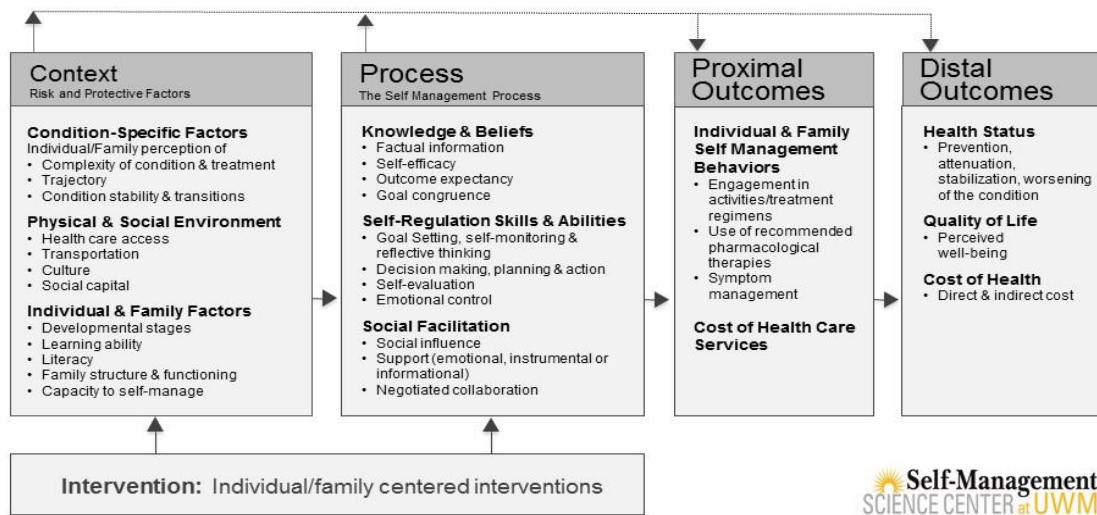
In 2013, Ryan and Sawin refined the theory based on evidence from studies that have helped to inform the model (Marek et al., 2013). In the process dimension, knowledge and beliefs were expanded to include factual information and collaboration was broadened to negotiated collaboration as one of the social facilitation factors. In addition, proximal outcome factors are more clearly delineated and are comprised of specific individual and family self-management behaviors listed as engagement in activities and treatment regimens, symptom management and use of recommended pharmacological therapies. The distal outcome factor, health status, now includes prevention, attenuation, stabilization, and worsening of the condition. All of the above

modifications were previously only listed in the theoretical definitions and were not specifically included in the model diagram. Individual and family centered interventions have been added as a separate dimension that may impact both the context and process dimensions.

Figure 1.1 Ryan and Sawin’s Model

Individual and Family Self-Management Theory

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Ryan, P.A., & Sawin, K. J. (2014). Individual and Family Self-Management Theory [Figure]. Retrieved from www.nursing.uwm.edu/smsc

Figure 1.1 Ryan, P. & Sawin, K.J (2009) The Individual and Family Self-Management Theory: Background and Perspectives on Context Process and Outcomes. *Nursing Outlook*, 57, 217-225.

Ryan, P. (2009). The integrated theory of health behavior change: background and intervention development. *Clinical Nurse Specialist*, 23(3), 161-170.

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Assumptions of the Model

1. Persons engage in behaviors for personally meaningful reasons that may or may not be directly related to optimizing their health status.
2. Many factors influence behavior, including personal preferences, culture, social norms, and family rules and boundaries.
3. Numerous contextual factors affect an individual's and family's ability and desire to engage in self-management.
4. Individual and family perceptions of resources affect engagement in self-management behaviors.
5. Self-management involves dynamic iterative processes requiring time, repetition, and reflection.
6. Social facilitation can direct, encourage, and support engagement in self-management behaviors and achievement of outcomes.
7. Person/family-centered interventions are most effective in fostering engagement in self-management behaviors and achievement of proximal and distal outcomes.
8. The concepts of adherence, alliance, and compliance are perceived contrary to self-management as they dismiss the notion that the primary responsibility and control lie with the individual or family.
9. Individuals are actively engaged in self-managing conditions by collaborating with persons in the health care system in order to achieve personal health goals.
10. Individuals and families engaging in health promotion behaviors may or may not collaborate with persons in the health care system.

The Conceptualization of the Model for this study

The IFSMT model is useful in describing the relationship between individuals and families providing complex care of adults with home PN. The key concepts and constructs have been adapted to address the factors integral to this population with the hope of gaining insight into the relationships among critical concerns.

Figure 1.2 Study Model

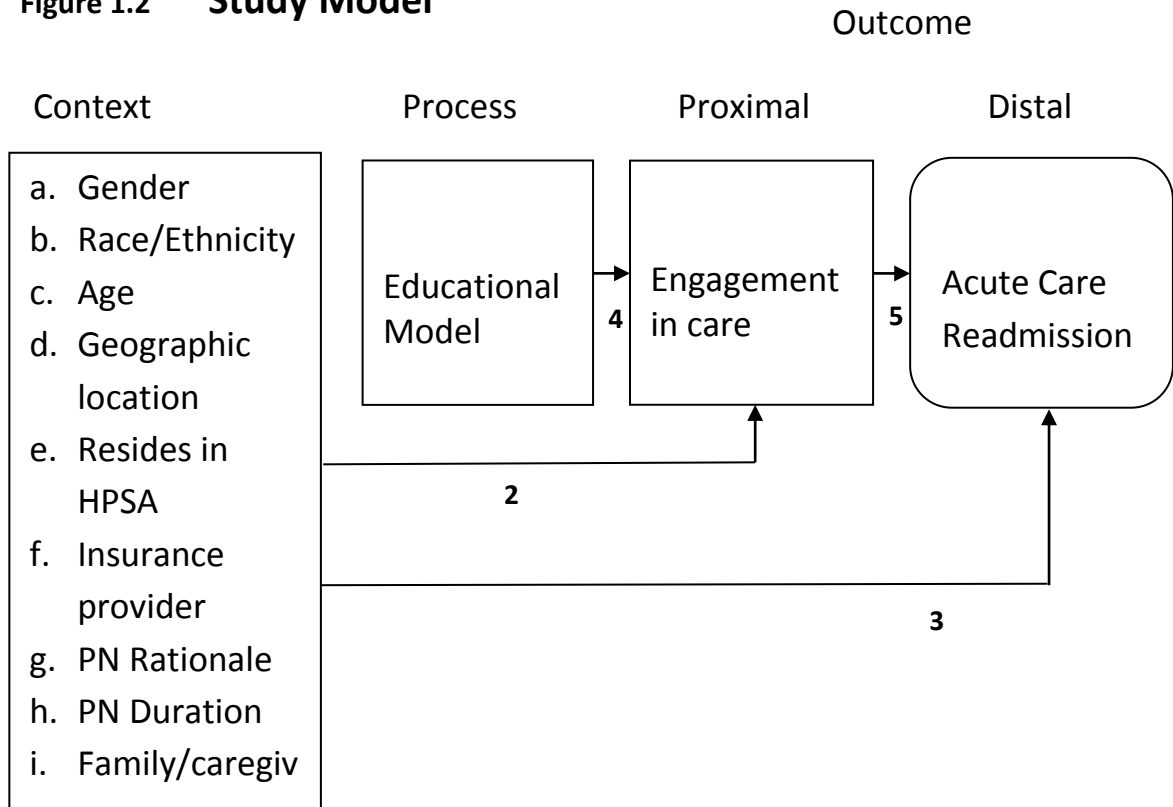


Figure 1.2: Adapted model from: Ryan, P. & Sawin, K. (2009). The individual and family self-management theory: Background and perspectives on context, process and outcomes. *Nursing Outlook*, 57, 217-225; Updated Individual and Family Self-Management Theory Model, Ryan, P. & Sawin, K. (2013).

Assumptions of the Study

The assumptions are derived from the IFSMT model but modified to reflect the purpose of this study.

1. Individuals and families have different learning styles and levels of health literacy that may affect how they interpret and implement care guidelines for managing home parenteral nutrition.
2. The concept of engagement is meaningful in this model because it infers a knowledge and skill-based commitment to self-management of care.
3. The individual and family have a right to decide if they will engage in self-management behaviors.
4. The conceptualization of resources in this model is multidimensional and encompasses personal, family, physical, functional, social and financial capabilities.
5. Individuals and families who live geographically distant to health care providers experience more challenges in addressing care needs.
6. A person's age alone, does not preclude them from being a candidate for home parenteral nutrition therapy.

Research Questions

The research agenda recently released by ASPEN (2013) indicates among many other issues, that there is a need for wider examination of clinical outcomes associated with malnutrition in all settings where nutrition support is provided. In addition, evaluation of the impact of the multidisciplinary nutrition support on clinical outcomes warrants further study. (Chan, Compher, DiBaise, DeMaria-Ghalili, Guenter, Resnick & Ziegler, 2013).

Therefore, the following research questions will be addressed:

1. What are the context dimension characteristics (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) of individuals and families managing home PN in this sample?
2. What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, and family/caregiver support) and the proximal outcome variable, individual and family engagement in care?
3. What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the distal outcome variable, acute care readmission?

4. What is the relationship between the process dimension factor, type of educational model utilized, and the proximal outcome variable, individual and family engagement in care?
5. What is the relationship between the proximal outcome variable individual and family engagement in care, and the distal outcome variable acute care readmission?

Theoretical Definitions

The major definitions of the IFSMT concepts have been delineated by Ryan and Sawin (2009) and are provided here. The 2013 model is comprised of all the major concepts initially introduced in the 2009 version of the framework, however some concepts initially described only in the theoretical definitions have now been rearticulated and integrated into the dimensions of the updated model. The theorists have not yet updated the theoretical definitions to reflect the new or rearticulated concepts introduced in the 2013 model.

Context Dimension

The concepts included in the Context dimension are categorized by either as condition-specific, physical and social environment or individual and family factors.

Condition specific factors are defined as physiological, structural, or functional characteristics of the condition, its treatment, or prevention of the condition that impact the amount, type, and critical nature of behaviors needed to manage the condition during times of stability or transition.

Physical and social environment factors are described as access to health care; transition in healthcare provider or setting; transportation; neighborhoods; schools; work; culture; and social capital that enhance or present barriers to individual and family self-management.

Individual and family factors are individual cognitive status; perspectives; information processing; developmental stages; individual and family capabilities

and cohesion; literacy and resourcefulness (Ryan & Sawin, 2009, p. 225).

Process Dimension

The Process dimension concept definitions are divided among three groupings: knowledge and beliefs, self-regulation skills and abilities and social facilitation.

Knowledge and beliefs are comprised of factual information and perceptions about a health condition or health behavior including self-efficacy, outcome expectancy, and goal congruency.

Self efficacy refers to the degree of confidence one has in his or her ability to successfully engage in a behavior under normal and stressful situations.

Outcome expectancy is the belief that engagement in a particular behavior will result in desired outcomes.

Goal congruence is a person's ability to resolve confusion and anxiety occurring from apparent contradictory and competing demands associated with health goals (Ryan & Sawin, 2009, p. 225).

Self-regulation is an iterative process people engage in to achieve a change in health behaviors. Skills and abilities such as goal setting; self-monitoring and reflective thinking; decision making; planning and action; self-evaluation and management of responses are the skills and abilities associated with self-regulation.

Social facilitation is the final grouping in the process dimension and can enhance an individual's capacity to change; it includes social influence, support, and negotiated collaboration.

Social influence is a message or dialogue in which respected persons in positions of perceived authority with expert knowledge advise and encourage individuals and families to engage in specific health behaviors.

Social support consists of emotional, instrumental or informational support provided with the explicit goal of assisting or facilitating engagement in health behaviors.

Negotiated collaboration occurs when individual perspectives are respected and influential. Professional expertise and standards, individual meaning and mutual family roles and responsibilities influence goals and recommended treatments. (Ryan and Sawin, 2009, p. 225).

Outcome dimension:

The components of the Outcome dimension are distinguished as either proximal or distal.

Proximal outcomes are defined as:

Individual and family self-management behaviors including engagement in activities and treatment regimens; symptom management and use of recommended pharmacological therapies. Engagement in health behaviors may or may not impact cost of health care services.

Distal outcomes are:

Health status as an indicator of the disease trajectory including prevention, attenuation, stabilization and worsening of the condition; quality of life and perceived well-being and direct and indirect costs (Ryan and Sawin, 2009, p. 225).

Summary

This chapter emphasized the necessity for further study of the issues and factors that individuals on home PN therapy and their families are handling. Nurses are integral members of the interdisciplinary team caring for these individuals across the continuum of care and it is important that they are aware of the problems, supportive interventions or actions and barriers to optimal health outcomes that may result. This study explored a model that may add to the body of knowledge on home parenteral nutrition therapy.

Chapter 2

Literature Review

The purpose of this exploratory, descriptive retrospective analysis of an existing data set was to examine the Individual and Family Self-Management Theory (IFSMT) and the relationships among the context and process factors and proximal and distal outcomes among adults on home parenteral nutrition (PN) and their families. The review of the literature encompasses: the science of parenteral nutrition therapy, complications and the risk for readmission, home parenteral nutrition management, self-management, and engagement in care.

Parenteral Nutrition Therapy

The indication for using parenteral nutrition is based on the remaining bowel anatomy and the functionality of the gastrointestinal tract. There are two primary rationales or indications for using PN. The first is malnutrition along with the inability to tolerate enteral feeding. Secondly, the interrelated conditions of malabsorption and short bowel syndrome which can lead to intestinal failure.

Malnutrition and inability to tolerate enteral feeding

Recommendations for determination of malnutrition provided by White et al. (2012) are: insufficient energy intake, weight loss, loss of muscle mass, loss of subcutaneous fat, localized or generalized fluid accumulation that may mask weight loss, and diminished functional status as measure by handgrip strength. Enteral feedings (EN) are supportive nutrition given by nasoenteric (gastric or small intestine)

tube, percutaneous endoscopic gastrostomy (PEG) tube or jejunostomy tube that can provide the necessary nutrients to address malnutrition in many instances and is usually attempted before parenteral nutrition is initiated (ASPEN, 2014). In addition to providing macro and micronutrients, enteral nutrition is beneficial with maintaining gut immune function and integrity (Worthington & Gilbert, 2012). There are times when enteral feedings are accompanied by parenteral nutrition therapy to assure nutritional needs are fully addressed. When enteral feedings, however, are not tolerated for instance with prolonged post-operative ileus, and the risk for malnutrition persists, parenteral nutrition is the option of choice.

Thomson (2008) conducted a meta-analysis on decision-making regarding the use of enteral or parenteral support. With an emphasis on robust methodology, he reviewed five prior meta-analyses conducted by researchers in the U.S., Canada, U.S./Scotland and two from Australia and concluded that deciding which therapy is most appropriate is a complex process but largely depends on intestinal function. No differences in mortality were noted between enteral and parental therapy in the US, Canadian, U.S./Scotland or one of the Australian meta-analyses; the second Australian analysis reported lower mortality with PN use. Other outcomes reported were increased incidence of infection in PN patients, decreased length of stay for EN patients, and increased hyperglycemia in PN patients with acute pancreatitis and critically ill patients. Recommendations included a more comprehensive evaluation including assessing absorption and metabolism of the chosen therapy, ongoing assessment of GI tract or venous access and a strong suggestion for a more rigorous scientific approach to the decision-making process.

Intestinal failure, malabsorption and short bowel syndrome

When PN is initiated due to intestinal failure, malabsorption and short bowel syndrome, gastrointestinal function and remaining anatomical structures help guide the decision to begin parenteral therapy. A number of studies have examined these indications for PN. Kalaiselvan et al., (2014) conducted a retrospective study in the UK of 611 patients with intestinal failure over a 13 year period and determined that the causative factor of failure in 32% of the subjects was radiation enteritis among those who had undergone pelvic radiotherapy. Although both EN and PN were prescribed, patients who required PN required long-term therapy.

Persons with advanced cancer may also be prescribed home PN because of bowel obstruction leading to intestinal failure resulting from either progression of their disease or complications of treatment modalities such as radiation therapy (Soriano & Davis, 2011). Duerkson et al., (2004) conducted a retrospective review of a small sample of nine, but found that patients with malignant obstruction benefitted from parenteral nutrition and survival rates were prolonged by as much as 60 days. Fan's retrospective study (2007) concluded that one year palliative care survivors in China could benefit from initiation of parenteral nutrition. He reported that the median time from when PN began until death was 6.5 months. Brard et al., (2005) had less promising results and reported a four week increase of survival for terminally ill ovarian cancer patients but if the women received concurrent chemotherapy, the survival time decreased. Increased tumor growth with the use of parenteral nutrition has been reported in a literature review conducted by Bozzetti & Mori, (2009). The researchers concluded that enteral and parenteral nutrition should be considered a treatment option when treatment of weight loss and starvation-related malnutrition benefits are greater

than risks associated with increased growth of the tumor (Bozzetti & Mori, 2009). Dev, Dalal & Bruera's review (2012) was contrary to the previously discussed studies stating that there is no clear evidence that feeding at the end of life is beneficial even though even though the decision to end feeding is found to be distressful for families.

Malabsorption may accompany short bowel syndrome thus the conditions are jointly reviewed. Parekh & Steiger (2007) define short bowel syndrome as "less than 200 cm of remaining viable jejunum and ileum following surgical resection for disease, trauma, infarction or congenital defect" (p. 10). Sequelae of short bowel syndrome may include: Gastric acid hypersecretion, inactivation of endogenous pancreatic enzymes, rapid intestinal transit, reduced absorptive surface area and small bowel bacterial overgrowth that may impact the degree of malabsorption experienced (Parekh & Steiger, 2007). One of the treatment goals in addressing short bowel syndrome is to increase the bowel's absorptive capacity in an effort to improve electrolyte, fluid and nutritional status (Parekh & Steiger, 2007). PN is one of several modalities including intestinal rehabilitation and intestinal transplantation that has been effectively used to treat short bowel syndrome.

Complications and Risk for Acute Care Readmission

Because PN is a serious therapy with a potential for adverse consequences particularly with long-term use, it is important that it is prescribed only when other less invasive options have been attempted and been unsuccessful. PN associated complications include: catheter-related blood stream infections (CRBSIs), dehydration, metabolic bone disease and liver damage and all are associated with increased risk for acute care readmission due to the treatment necessary to address the complication.

Among complications associated with PN therapy are tunnel and exit site infections along with catheter-related blood stream infections (CRBSIs) are significant in this population (de Burgoa et al., 2006; Kirby et al., 2012; Shatnawei et al., 2010; Wischmeyer et al., 2013). Other researchers have reported increased morbidity and mortality related to these infections (Elfassy, Kassam, Amin, Khan, Haider & Armstrong, 2013; Gillanders et al., 2012).

In a retrospective analysis of patients from January, 2006 to August 2009, John et al., (2011) examined CRBSI rates and reported that safety and efficacy could be maintained while decreasing CRBSI rates and subsequent hospital readmission with the instillation of ethanol after completion of PN infusion – formally referred to as ethanol-lock therapy (ETL). A comparison of hospital readmissions of home PN and skilled nursing facility patients using ETL found that there were fewer readmissions of skilled nursing facility patients using the ethanol lock therapy as compared to those on home PN using ELT or not using ETL in a retrospective review of charts from January, 2010 to March, 2011 conducted by Corrigan, Pogatschnik, Konrad & Kirby (2012). Corrigan & Kirby (2012), retrospectively examined six case reports of individuals who were unable to continue with ethanol-lock therapy due to drug shortages experienced in the United States in 2011 and discovered that CRBSI rates immediately increased with in these individuals.

The literature is replete with additional studies inconsistent in scientific rigor discussing CRBSIs and associated interventions to decrease the prevalence infection among the home parenteral nutrition population within the United States and internationally. Dreesen et al. (2012) however, conducted a systematic review the body

of knowledge on catheter-related infections in adults on home PN to determine infection pathogen and incidence and contributing factors. Thirty-nine of the more rigorously conducted studies of scientists from 14 different countries published between 1984 and March, 2012 were examined. The commonly reported pathogens were Staphylococcus for gram positive bacteria; Klebsiella pneumoniae was most the most frequently identified gram negative bacteria and for fungal sources, the pathogen was Candida.

The researchers summarized risk factors as device-related, education-related, follow-up related, patient-related and therapy-related (Dreesen et al., 2013). Device-related factors had to do with central catheter type specifications in particular, the Hickman, peripherally inserted central line (PICC), and infusion port. Higher infection rates were reported with PICC lines as compared to tunneled lines (DeLegge, Borak & Moore, 2005). Double lumen catheters (Raman, Gramlich, Whittaker & Allard, 2007), as well as jugular vein cannulation and use of catheters greater than 2 mm in caliber (Bozzetti, et.al., 2002), were associated with higher infection rates. Some studies reported infection rates as higher for infusion ports when compared to Hickman's, (Bozzetti, et.al., 2002; Santarpia, et al., 2002; Santarpia, et al., 2010); but others did not report these findings (Pironi et al., 2003; Reimund, Arondel, Finck, Zimmermann, Duclos & Baumann, (2002); Shirotani, Lino, Numata & Kameoka, 2006).

Education-related risk factors were had to do with instruction received prior to initiating home PN therapy. In studies conducted by Santarpia, and colleagues, 2002 and Bonifacio, and colleagues, 2007, those who received comprehensive home training had lower CRBSI rates.

Follow-up related risks included home care nurse involvement and was reported as helpful in one study if the nurse had specialized training (Bozzetti, et al., 2002). Another study indicated nurse involvement was not a significant factor in reducing CRBSI rates (O.Keefe, Burners & Thompson, 1994). Infection rates increased if the patient had more dependents (Chang, Enns, Saqui, Chatur, Whittaker & Allard, 2005) or if a family member cared for them as reported in studies by Chang et al., (2005) and Bozzetti, et al., 2002).

Patient- related factors that contributed to increased risk were opiate and sedative dependence and bowel length, specifically, those with shorter lengths tended to have increased risk. Patients with Crohn's disease tended to have more infections which was thought to be related to immune deficiencies associated with the condition (O'Keefe, et al., 1994). Terra et al., (2000) and Reimund, et al., (2002) both reported that patients with shorter lengths of bowel were more likely to have infections.

Finally, therapy-related factors had to do with the length of time on PN with one study reporting that those receiving PN for seven or fewer days had decreased risk (Bozzetti, et al., 2002) but two other studies did not show significant risks for longer periods of therapy (Reimund, et al., 2002; Pironi et al., 2003).

Dreesen et al. (2013) provided several important recommendations. First, a need for standardization in operational definitions emphasizing that evidence-based published guidelines should be the standard of care for management of central lines. A second recommendation was that ongoing proper training is essential for all persons prescribed this therapy. Thirdly, the use of tunneled-catheters such as Hickman catheters is preferable. Additional randomized controlled trials should be conducted for

catheter dwell agents that aim to decrease the risk of bacterial growth such as Ethanol-lock (Corrigan, Pogatschnik, Konrad & Kirby, 2012; John et al., 2011) and Taurolidine lock, an antimicrobial agent (Klek, Szczepanek, Hermanowicz & Galas, 2014) to add additional research-based evidence for continued use of these drugs.

Factors leading to complications occurring within 90 days of discharge were examined prospectively by de Burgoa, Seidner, Hamilton, Stafford & Steiger (2006). Infectious, mechanical and metabolic complications were found to be most prevalent among the sample of patients examined from June 2003 and July 2004 and the majority of patients were hospitalized for complication-related treatment. Metabolic complications include dehydration and electrolyte and blood glucose abnormalities. Persons with malabsorption, obstruction or a fistula are at risk for becoming dehydrated with prolonged use of home PN and home IV fluids (deBurgoa et al., 2006; Konrad, Corrigan, Hamilton, Steiger & Kirby, 2012). Early identification for those at risk requires a comprehensive evaluation of objective and physical data indicating a need for additional hydration. Furthermore, providing patients with dehydration indicators so they can take steps to prohibit it from occurring and equipping individuals with additional IV hydration solution for infusion should be a part of the protocol for managing dehydration in an effort to decrease the risk for acute care readmission (Konrad et al., 2012).

Correction of metabolic complications related to PN therapy may only be partially modifiable by altering the PN components. Additional supplements and mechanical ventilation at times are indicated for weakened respiratory muscles according to Dodds, Murray, Trexler & Grant (2001). Untreated electrolyte

abnormalities not only produce undesirable health outcomes, but can become costly due to additional interventions and treatments necessary to correct abnormalities (Dodds et.al, 2001). Therefore, the Standard care for management of electrolyte abnormalities is that they are treated before the patient becomes symptomatic. Individuals managing PN at home must be engaged in their care regimens and self-monitoring and they along with the home care agencies assisting in their care are to report abnormal values and physical or objective variations to health providers when noted. Metabolic bone disease and liver disease are potential complications of long-term PN use (Shatnawei et al., 2010). Osteoporosis and osteomalacia, the two most common types of metabolic bone disease (MBD) have an increased prevalence among the long-term PN population. However, the mechanism for why this occurs and the exact incidence is unknown (Seidner & Licata, 2000). Bone pain and fractures might be the clinical presentation or the individual may not experience any symptoms at all (Ferrone & Geraci, 2007). Therefore, health providers are cautioned to evaluate for bone changes in persons who require PN within the first year of therapy (Shatnawei et al., 2010).

Raheem et al. (2013) did a retrospective review of complications experienced among home PN dependent individuals that occurred following bariatric surgery that led to small bowel transplantation with the focus on four cases. The investigators recommended that patients considering bariatric surgery be presented with full details of possible serious and sometimes life-threatening complications that may occur prior to undergoing this surgery. CRBSI and morbidities related to short bowel syndrome and intestinal failure led to acute care readmission with these subjects.

Desmoid tumors are a rare condition that occurs in twelve to fifteen percent of those with familial adenomatous polyposis (FAP), (Shatnawei, Hamilton, Quintini, Steiger & Kirby 2010). Desmoid tumors are non-metastatic invasive soft tissue tumors that may lead to enterocutaneous fistulae, short bowel syndrome or small bowel obstructions (Shatnawei, et al., 2010). In a retrospective case-control study for the years 1990-2008, Shatnawei et al. (2010) found that home PN use did not increase serum albumin levels even though these patients received more that the controls. They also discovered that PN helped to maintain BMI in those with desmoids, that there was no increase in complications experienced as compared to those without desmoids.

Shatnawei et al. (2013) conducted a retrospective analysis of 154 subjects with FAP and desmoids separated by those on home PN, n=41(26.6%) or no home PN, n=113 (74.4%). They discovered that those who required home PN as a part of their treatment regimen were more likely to have a poorer prognosis and had increased morbidity and mortality. Subjects requiring home PN also tended to have more advanced conditions and experienced chronic abdominal pain, bowel or ureteral obstruction, narcotic dependency, deep vein thrombosis, pulmonary embolism, fistulae and sepsis. Much of the treatment for acute problems related to FAP and intra-abdominal desmoids requires hospitalization.

Liver failure has been reported as a complication of long-term use of PN (Putchakayala, Polensky, Fitzhugh, Cohran, Buchman & Fryer, 2009; Shatnawei et al., 2010). Salvino, Ghanta, Seidner, Mashca, Xu & Steiger (2006) make a distinction in that abnormal liver enzymes are common, but severe liver failure occurs infrequently. Gabe (2013) concurs with the commonality of abnormal liver enzymes and suggests

that dosing of lipid emulsions which usually accompany PN therapy be modified to minimize risk of liver damage. Putschakayala et al. (2009) reported in a case controlled retrospective study that C-reactive protein (CRP), an acute inflammatory indicator, along with the model for end-stage liver disease (MELD) may be promising clinical markers for prediction liver disease progression and of mortality associated with PN related intestinal failure.

Home Parenteral Nutrition Management

Complex Technology-based Care

Complex chronic care as described in the literature refers to caring for persons with more than one chronic illness or condition such as diabetes, hypertension, congestive heart failure or chronic obstructive pulmonary disease (CMS, 2013; McNabney et al., 2014; Tsasis & Bains, 2008). The body of knowledge on parenteral nutrition therapy consistently describes management of PN as complex and multifaceted care. Complications and comorbidities that may occur are an unfortunate accompaniment to a known multidimensional care routine that may necessitate additional treatment such as antibiotic administration and ostomy care.

Use of technology is integral to home PN care requiring individuals and their caregivers to acquire knowledge and skills essential to safe and effective therapy management. Technology-based care extends beyond the care of persons with multiple chronic conditions to include the essential technology that becomes sustenance for existence. Smith, Giefer & Bieker (1991), Smith (1994) & Persoon, Huisman-de Waal, Naber, Schoonhoven, Tas, Sauerwein & van Achterberg (2005) among others examined the use of technology in the PN population. Winkler, Ross, Piamjariyakul, Gajewski &

Smith (2006) conducted an extensive review of research on the impact of technology dependence in home care which included not only the PN population, but persons on dialysis, ventilators, tube feedings, IV medications and combinations of these groups. Technology was described as negatively influencing quality of life.

Smith, Giefer & Bieker (1991) conducted a pilot study to test a preliminary model aimed at exploring patient and family adaptation to care, technology and responsibilities of home PN management in rural settings. Persoon, Huisman-de Waal, Naber, Schoonhoven, Tas, Sauerwein & van Achterberg (2005) examined the impact of long-term HPN use on daily life. They identified problems in managing and coping with the technology along with the complexity of management.

Caregiving and Social support

A number of researchers have contributed to the body of knowledge on the care of individuals on home PN. Smith and colleagues developed, tested (Smith, Giefer & Bieker, 1991), replicated (Smith, 1994; Smith, 1999) and refined a mid-range theory of home care, the Caregiving Effectiveness model (Smith, Pace, Kochinda, Kleinbeck, Koehler & Popkess-Vawter, 2002). The model was utilized to examine technologically dependent client populations inclusive of those on home PN. The framework has theoretical underpinnings in the Roy Adaptation model and provides a structure for examining family caregiving in the context of technologically dependent adults who participate in their own complex care (Smith, 1994). The model describes caregiving and adaptive contexts in relation to caregiving effectiveness. Patient and caregiver quality of life, patient condition and technological side effects are the four caregiver effectiveness measures. Empirical testing of the model occurred with heart failure

(Scott, 2000) and home PN populations (Smith et al., 1991; Smith, 1994, 1999, Smith et al., 2002) with evidence of model validity in both groups. Researchers using the caregiver effectiveness model have made a significant contribution to the growing body of evidence and have advanced the science guiding the care of individuals on PN and their caregivers. This model examines individual and caregiver concerns, but further work is needed in the exploration of self-management skills and health outcomes of those with home parenteral nutrition.

Quality of life

Researchers from multiple disciplines have examined quality of life (QOL) in the home PN population from a variety of perspectives. Malone (2002) conducted a longitudinal assessment of 13 home PN patients and found that health status was stable for persons with no history of malignancy. The Short Form (SF) 36, a standardized health-related quality of life instrument was utilized. Respondents reported that sleep, travel and social activities as well as their overall lifestyle was significantly affected due to PN.

Reactive depression in home PN patients and family caregivers was reported in studies by Smith et al., (1991); Smith (1994) and later by Smith et al., (2002) and Smith, Leenerts & Gajewski (2003b). The Center for Epidemiological Studies – Depression Scale (CES-D) scores were obtained before and after nurse taught Journal Writing Interventions. Improved CESD scores were reported as the journaling length of time increased in the patient group in the Smith et al., in (2003a) and (2003b) studies. Themes from the journaling included financial concerns, missing out on activities,

financial stress and concern about serious illness and the complexity of care (Smith et al., 2003b).

Winkler (2005) conducted a comprehensive review of the literature of a total of 24 studies from 1982 to October 2003 inclusive of quantitative and qualitative research examining quality of life of adult home PN patients. Quality of life was found to be poorer in long-term home PN patients. Difficulties with eating, sleep disturbances, fear of complications, depression and frequent urination reported as having a negative impact on quality of life.

Emotional distress or representation such as feelings of anxiety, upset, anger, fear and low mood were reported by Fortune, Varden, Parker, Harper, Richards & Shaffer (2005) in a study of 61 intestinal failure patients on home PN in the United Kingdom. Patient's perceived personal control and understanding of their illness (illness coherence) were the primary predictors for emotional distress (Fortune et al., 2005).

Persoon et al., (2005) and Huisman-de Waal, Naber, Schoonhoven, Persoon, Sauerwein & van Achterberg (2006) examined psychosocial problems along with physical problems in 48 individuals on home PN in the Netherlands via questionnaires and/or open structured interviews. The mean duration on PN was 4.6 years. Reported psychosocial problems were comparable to those mentioned by Fortune et al., (2005) with anxiety being reported in about one third of the participants. Other responses included fear of dying, frustration with their appearance, feeling left out, and that others did not understand their experience. Others felt they were a burden to their families and that being dependent on HPN for survival was an unpleasant and undesirable option.

Frustration with social limitations and feeling incapable were also expressed. Physical complaints reported were associated with their reason for needing PN, but most individuals said they were fatigued and unable to keep up with usual activities and responsibilities. Experiencing complications and financial issues were also concerns for respondents. There was a small group of individuals who indicated that they had adjusted to life with home PN (Huisman-de Waal, et al., 2006).

Findings from a 2010 study by Huisman-de Waal et al., were similar to those of the 2006 study however an association in complications experienced and psychosocial problems reported was identified. The researchers emphasized the relationship was not causal, but that assessment of the occurrence of both problems and complications warranted further evaluation and treatment.

An interpretative phenomenological qualitative study utilizing semi-structured questionnaires on the meaning of food and eating was conducted by Winkler, Wetle, Smith, Hagan, O'Sullivan Maillet & Touger-Decker (2010). Twenty-four individuals on home PN with intestinal failure participated in this inquiry. Twenty-three of the participants were able to eat food and the other individual ate on an intermittent basis due to concern for dysmotility issues. A conceptual model was also proposed as a framework for studying relationships among patterns of eating and physical and emotional attributes. The researchers surmised that food and eating are important to study participants and having the capacity to eat affected a person's perceived quality of life. Strategies to manage social and family situations were offered and further investigation is recommended.

Baxter, Fayers & McKinlay (2005) reviewed the literature on instruments researchers used to evaluate health related quality of life among individuals on home parenteral nutrition. Because of the expressed concern for quality of life for those on PN therapy and the evidence supporting a need for accurate and timely evaluation of problems, in 2010, Baxter et al., 2005 introduced a quality of life instrument specifically intended to address documented issues affecting these individuals. The HPN-QOL measure is a 48 item scale consisting of functional and symptom subscales with questions on physical symptomatic and emotional concerns. The Cronbach's alpha on subscales ranged from 0.45 to 0.88 and criterion validity was not fully discussed; other instrument quality indicators such as interrater reliability and construct validity were not addressed. As a consequence, further instrument validation is suggested.

Self-Management

Self-management is integral to achieving optimal health care outcomes in all settings of care and in life in general. Internationally, scientists have explored self-management from a plethora of perspectives and paradigms and evidence-based knowledge has been created that informs health care practice. Countless researchers have contributed to the science on self-management of chronic illness and diseases. Lorig & Holman, 2003 discussed in depth the history, definition, outcomes and mechanisms of self-management. In addition, Lorig and colleagues, have over several decades, extensively examined self-management behaviors among those with one or more chronic conditions including diabetes (Jernigan & Lorig, 2010; Lorig, Ritter, Ory & Whitelaw, 2013); and arthritis (Lorig, Laurin & Holman, 1984; Lorig, Mazonson &

Holman,1993). Lorig and fellow researchers have also examined patients with multiple conditions such as: heart disease, lung disease, and stroke, (Lorig, et al., 1999; Lorig, et al., 2001a; Lorig, et al., 2001b; Lorig, Ritter &Gonzalez, 2003) along with other comorbidities utilizing the Chronic Disease Self-management Program (CDSMP) interventions. The scientists conducting these studies using the CDSMP indicate that health outcomes were improved with the implementation of self-management activities and behaviors as compared to those who did not have self-management training. Ongoing investigations and a number of literature reviews on the science of self-management have been conducted on various populations. Improvement in health outcomes to some extent is reported in most all of the investigations even though there are inconsistencies in reporting details of measures and data analysis procedures. Studies of representative of the body of knowledge in self-management are reviewed here.

Robinson, Thompson, Wilkin & Roberts (2001) conducted a randomized controlled trial examining self-management of patients with ulcerative colitis. There is no mention of home PN use in this study, but ulcerative colitis is the third most common reason for PN being prescribed. Two hundred three patients participated in the study. The intervention group received self-management training consisting of symptom recognition and medication management instructions with the goal of preventing relapse of the condition. Scheduled appointments were not made with those in the intervention group, but instead clinical parameters signaling the need to request medical advice such as unexplained weight loss or rectal bleeding were given to the intervention group. The control group received usual outpatient care with pre-arranged

follow-up visits. The researchers concluded that those who self-managed their disease were more likely to seek treatment earlier and had fewer physician visits without increasing morbidity.

Chronic disease self-management of diabetes has been explored recently by Lorig, Ritter, Ory & Whitelaw (2013). Statistically significant improvement in health indicators such as hemoglobin A1C and behaviors of study participants were found, but health care utilization was not decreased. Hill-Briggs & Gemmell (2007) and later Fitzpatrick, Schumann & Hill-Briggs' (2013) reviewed the literature on problem solving interventions and diabetes self-management of studies with children, adolescents and adults. Of the 36 studies in the Hill-Briggs & Gemmell (2007) examination and 24 investigations in the Fitzpatrick, Schumann & Hill-Briggs (2013), improvement in hemoglobin A1C was indeed noted in 50% of adults but only 25% of children/adolescents. The 2013 review revealed 36% of adults and 42% of child/adolescents using problem-solving interventions had statistically significant improvement in hemoglobin A1C levels, dietary adherence in adults, and global adherence in children and adolescents. Recommendations were consistent that more comprehensive descriptions of interventions were needed as well as the use of interventions with the potential to make a difference in outcomes (Hill-Briggs & Gemmell, 2007; Fitzpatrick et al., 2013).

Another literature review examined diabetes self-management and health outcomes among culturally diverse populations such as Black African/Caribbean and Hispanic/Latin American ethnicity and found that culturally tailored interventions and the use of dietitians as interventionists may be more effective in improving women's

self-management behaviors (Gucciardi, Chan, Manuel & Sidani, 2013). Other recommendations of the scientists were that hospital-based group interventions, situational problem-solving and frequent sessions were also found to have a strong positive effect on achievement of desired outcomes (Gucciardi et al., 2013).

Jernigan & Lorig (2011) conducted a pilot study as part of a larger trial that examined the feasibility of implementing the Stanford internet diabetes self-management program via the internet as a tool for teaching self-management skills to American Indians (AI) and Alaska Natives (AN). Recruitment efforts were tailored and included an AI/AN website that seemed to have a positive impact on participation. This is an indication that cultural considerations must be a part of the planning in self-management education if it is to be effective in facilitating change.

The daily life of individuals self-managing psoriasis was examined in a review by Rasmussen, Maindal & Lomborg (2012). The review consisted of 19 studies conducted in either Norway, United Kingdom, Poland, The Netherlands, the United States, Sweden, South Africa or Australia. Three key factors seemed to impact an individual's ability to self-manage: disease-specific factors related to symptoms and complications experienced; personal factors such as appearance and cosmetic issues; and, self-experienced burden of disease which may involve long-term management of this chronic autoimmune condition. The researchers recommended that educational programs should be designed with these important factors and any self-management support efforts should address these factors deemed to be pertinent to those with the condition particularly the youth (Rasmussen et al., 2012).

An asthma self-management literature review was conducted by Andrews, Jones & Mullan (2014) based on 64 studies conducted in Australia from 1995 through 2011. The researchers discovered that there was minimal adoption of self-management behaviors among the adult asthma population due primarily to low self-efficacy and health literacy. The findings also indicated that these patients tended to have few contacts with health providers sometimes seeing them only for treatment or emergent care, patient and family health education was not consistently a part of the care plan. Researchers also comment that the dynamic nature of asthma management does not necessarily lend itself to generic self-management programs not adapted to the needs of this population. It is interesting to note that these non- nurse researchers believe that nurses as members of an interdisciplinary health care team could have a crucial role in the implementation health education programs that would include teaching of self-management skills and strategies for better health outcomes (Andrews et al., 2014).

Lymphedema self-management was the focus of a review of the literature by Ridner, Fu, Wanchai, Stewart, Armer & Cormier (2012). The prevalence of lymphedema in the breast cancer population is well documented in the literature, but there is also a known incidence of lymphedema occurring with other types of cancer. The occurrence of lymphedema is an indication that care and management will be ongoing for a lifetime. Inconsistencies in outcome measures and lymphedema self-management behaviors were revealed among the 16 studies that were reviewed. The investigators emphasized the need for additional randomized clinical trials to continue to build the science of care and additional testing of effective self-management strategies to address all levels of lymphedema.

According to the literature review of 52 studies conducted by Aantjes, Ramerman & Bunders (2014), there is an extreme lack of self-management evidence to inform the care of persons living with the human immunodeficiency virus (HIV) in Sub-Saharan Africa as there were virtually no studies that addressed self-management. The Highly Active Anti-Retroviral Treatment (HAART) is not as broadly used in this region of the world and in 2011, there were approximately 23 million people in Sub-Saharan Africa living with HIV accounting for 69% of people worldwide with HIV (UNAIDS, 2012). HIV/AIDS management is ongoing and lifelong, yet the extreme shortage of health care providers decreases the likelihood of health professional led self-management programs being implemented and studies addressing community or family led programs were not found in the literature either. A tremendous need and opportunity exists for health care providers to affect the quality of health and life among this population.

A pilot study conducted by Webel, Moore, Hanson & Salata (2013) introduced a self-management intervention for people living with HIV that is systems based to encourage participation in physical activity as a way of minimizing the effects of co-morbidities that can accompany this condition. The intervention titled SystemCHANGE assisted 70% of the 40 participants in increasing their physical activity level.

Telehealth and self-management programs with the heart failure population were reviewed by Radhakrishnan & Jacelon (2012). The fourteen studies reviewed reported that telehealth improved self-care or self-management behaviors in heart failure patients in eight of the studies but there were no differences noted between the

experimental and control groups in five of the studies. The remaining study was qualitative and with themes supportive of telehealth use in heart failure self-management being reported.

In a pilot study with older adults living at home or in a skilled facility recovering from a cardiac event conducted by Dolansky, Zullo, Boxer & Moore (2011) a self-management but family supported intervention, Cardiac Transitional Rehabilitation Using Self-Management Techniques (Cardiac TRUST) was implemented. The intervention was found to assist elders in recovery through participation in cardiac rehabilitation programs as compared to older adults receiving usual care.

The concept of hope among adults with mental disorders was the basis of a review of literature by Schrank, Bird, Rudnick & Slade (2012). Hope measures utilized in psychiatric research, determinants of hope, self-management strategies and interventions that may increase hope were all examined as a part of the 57 studies reviewed. The investigators reported that self-management strategies that fostered hope were noted exclusively in the qualitative studies included in the review. Suggested self-management strategies for hope that were offered were to provide practical advice on issues affecting recovery such as managing illness; peer support; meaning, relationships, the idea of normality and an emphasis on success were deemed the most important (Schrank et al., 2012).

Jonker, Comijs, Knipscheer & Deeg (2009) reviewed nine studies on chronic self-management disease programs (CDSMP) among vulnerable older adults. CDSMPs were found to improve exercise and self-care behaviors as well as decrease reported distress. Self-efficacy, cognitive symptom management and mental stress management

were also improved and utilization of health care services remained stable and did not decrease.

The body of knowledge on self-management is vast and cannot be reviewed in its entirety here. The representative investigations reviewed demonstrate the value of self-management interventions and behaviors in the care and health of persons with one or more chronic conditions. It is apparent that tailoring, cultural considerations and the specific problems and potential complications that may affect a given population must be considered when designing programs and interventions for use with those individuals and their families. Feasibility studies and input from the target recipients of care appear to be helpful in refining interventions that may be most beneficial. The remainder of this review will focus on self-management processes and the core concepts of self-efficacy and engagement which are foundational to Ryan and Sawin's 2013 Individual and Family Self-Individual and family self-management theory model.

Self-management processes

A comprehensive evidence-based exploration of self-management processes was done by Schulman-Green et.al, (2012) who examined 101 studies published from January 2000 through April 2011. Three primary classifications of self-management processes that were identified from the synthesis: focusing on illness needs; activating resources and living with a chronic illness. These self-management processes are akin to the work done by Corbin and Strauss (1988) that examined persons living with chronic illnesses and delineated management of medical tasks, creating and adjusting to lifestyle changes and meaningful activities and coping with the emotions that come with living with a chronic condition.

Behaviors identified for each of the process categories were outlined. Activities associated with a focus on illness needs consisted of learning the tasks and acquiring the skills required for ongoing care and management of the chronic condition and symptoms associated with the illness. Accepting ownership for health needs as well as participation in health maintenance and promotion behaviors is an important activity in this category (Schulman-Green et al., 2012).

Processes affiliated with activating resources are maintaining communication with health providers, seeking psychosocial, spiritual, peer, community and financial resources to comprehensively address identified personal needs. The researchers emphasized that the resources an individual chooses to activate is based on personal preferences and the comfort level the person possesses in executing these contacts so variability and ongoing change is expected (Schulman-Green et al., 2012).

Living with a chronic illness is a dynamic adaptation that occurs depending on the particular needs with which one may be coping. Transition, coping, adaptation and integration to address needs are all concepts associated with self-management processes within this category. Processing of emotions, dealing with joys and grief, lifestyle modifications including personal and financial issues that accompany ongoing management of a chronic condition are behaviors that require consideration along the trajectory. Lastly individuals need to find purpose and meaning in living with chronic illness as well as ways to gain personal satisfaction as they adjust to the needs of the condition (Schulman-Green et al., 2012).

Self-efficacy

Self-efficacy is both a theory and concept described by Bandura. Perceived self-efficacy is defined as “people’s beliefs about their capabilities to exercise control over their own level of functioning and over events that affect their lives” (Bandura, 1991, p. 257). Self-efficacy influences behavior and the higher one’s perceived self-efficacy, the more likely one would feel confident in changing behavior (Bandura, 1977).

Bandura believed that, “Efficacy expectations determine how much effort people will expend and how long they will persist in the face of obstacles and aversive experiences and the stronger the perceived self-efficacy, the more active the efforts” (Bandura, 1977, p. 194). Individuals who have mastered an activity tend to display greater interest and possess a sense of accomplishment in what has been achieved (Bandura, 1991).

Efficacy expectations are beliefs that intentional actions will produce an outcome (Bandura, 1977). Self-efficacy is a core concept of Bandura’s Social Cognitive Theory which proposes that humans learn through observation or modeling, innate qualities and from environmental influences. Self-efficacy is also the basis for evidence-informed self-management programs created by Lorig, Bandura and colleagues.

Katch & Mead (2010) explored the self-efficacy as it relates to self-management in an examination of five evidence based cardiovascular disease self-management programs. Self-efficacy was viewed as an essential component for effective self-management and ongoing engagement in care. When a person believes that they possess the capacity and mastery to complete and fully participate in the needs at hand, a sense of accomplishment and gratification is experienced, thereby empowering them to persevere in new or challenging tasks (Bandura, 1977). Patients participating in programs that supported self-efficacy behaviors were more likely to have improved

outcomes. Other researchers reported similar positive outcomes with high self-efficacy and improved self-management among diabetes patients and increased glycemic control (Al-Khawaldeh, Al-Hassan & Froelicher, 2012); and with individuals who have had strokes (Jones & Riazi, 2011).

Engagement

The Ryan and Sawin IFSMT (2009, 2013) model includes the concept of engagement as a proximal outcome. Engagement in self-management is described as personal participation, or involvement, in care related to a condition that may include care regimens and symptom management (Ryan and Sawin, 2009). The concept of engagement from the patient and family perspective and health outcomes is inclusive of education, activation, involvement, informed decision-making and empowerment (Center for Advancing Health, 2010; Flynn and colleagues, 2012; Hibbard, Stockard, Mahoney and Tusler, 2004; Pelletier and Stichler, 2014).

Hibbard and colleagues (2004) discuss the conceptualization and operationalization the concept activation that lead to the development of the Patient Activation Measure (PAM) which is used to assess patient's ability to navigate to increased levels of involvement in their health and health care decisions through education and tailored coaching. A short form of the measure was introduced in 2005 (Hibbard et al., 2005). The researchers report improved health outcomes for the more activated individual, and believe that activation improves one's capability to self-manage care. Further investigation and use of the model is recommended for continued refinement of the concepts and applicability.

Gruman and colleagues (2010) define engagement as, “Actions individuals must take to obtain the greatest benefit from the health care services available to them” (p. 351). Forbat, Cayless, Knighting, Cornwell and Kearney (2009) believe that engagement embraces the idea of collaboration and participation extending beyond simply gathering information. Coulter (2011) broadens the definition to include health professionals and organizations: “Working together to promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions at both the individual and the collective level” (p. 10).

Carman, Dardess, Mauere. Sofaer, Adams, Bechtel and Sweeney (2013) describe confusion over the definition of engagement found in the literature but add their definition of patient and family engagement as, “patients, families, their representatives and health professionals working in active partnership at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health and health care” (p. 224). Engagement has been conceptualized in a multidimensional framework by Carman and colleagues (2013) as levels of engagement ranging from the concepts of direct care, to organizational design and governance then to policy change that can be influenced by the continuum of engagement. Factors along the continuum range from consultation, involvement to partnership and shared leadership. Clearly engagement can begin with patient and family caregivers self-managing and extend to collaboration with health providers, the health care system, and the community and beyond. If there is not engagement and empowerment on a personal level, however, is it likely that an individual will embrace engagement beyond that realm?

A strategic goal of the American Academy of Nursing (AAN) for the years 2014 – 2017 is to promote policies that are evidence-based and encourage both patient and family engagement in decisions about their health (AAN, 2014). Compliance is often used by health providers when describing patient's responses to instructions or when referring to the tasks and regimens that are a part of home PN. Compliance however infers that directions need to be followed in order to achieve the desired outcome and patient input is not necessarily sought. Engagement, however, is much more participatory and empowering and individuals are encouraged to provide and share in decision-making. The paradigm shift to engagement has occurred throughout the health care industry particularly in the United States. The principles and strategies of engagement in health care decisions are fundamental to the initiatives of the Affordable Care Act. It is an expectation that health care institutions will make an individual's health information available in a way that is meaningful, understandable and useable that can inform decisions about one's state of health. Individuals and families managing home PN are expected to make numerous care decisions daily that require discernment and critical thinking. It is hypothesized that home parenteral nutrition therapy is optimally managed when there is engagement among persons and their families.

Summary

The current study is important because the literature is lacking in studies examining self-efficacy, engagement and self-management in the parenteral nutrition population from the perspective of Ryan and Sawin's theory. The multidimensional perspective of this model fosters its use with the complex needs of the population because it has the potential to further inform the science.

Chapter 3

Methods

The purpose of this exploratory, descriptive retrospective analysis of an existing data set was to examine the Individual and Family Self-Management Theory (IFSMT) and the relationships among the context and process factors and proximal and distal outcomes among adults on home parenteral nutrition (PN) and their families. The requirements for home PN use, the parenteral nutrition database and data collection for the database are reviewed. The study design, sample, setting, measures, data management and analyses are also discussed in this chapter.

Requirements for home PN therapy and nutrition support team management

Home PN therapy requirements are as follows: a physiological need for PN as determined by established parameters including failure of enteral nutrition therapy; interdisciplinary team evaluation and approval for home PN management; insurance benefits or financial resources supportive of home PN; a designated primary caregiver which in some cases may be the individual; must be willing to utilize translation services to facilitate communication if English is not their primary language and have at least met the minimum standards for safe home PN administration as determined by the nutrition support teams. Persons for whom there is concern for psychosocial issues are referred for an in depth social work assessment, which may also include further evaluation by a psychiatrist or other specialists or health care professionals

Reasons that patients would not be accepted for home PN management by the nutrition support teams include: failure to meet standards for safe use of the therapy;

lack of capacity or unwillingness to complete care regimen; a history of substance abuse particularly intravenous abuse and lack of a clean, safe home environment or insufficient insurance benefits or financial resources that are accommodating to home PN therapy. Persons with insurance eligibility concerns may receive therapy initially with an interim benefit in a skilled facility while comprehensive coverage is sought.

Home Parenteral Nutrition Database

The dataset for this study is inclusive of data extracted from the Institutional Review Board approved Home total parenteral nutrition database that was originally approved in 2002. The database was created to gather information essential for safe and comprehensive management of adults being followed by the Nutrition Support team in acute care and Home Nutrition support in the outpatient setting. All persons who have met the requirements for home PN therapy and are being managed by the nutrition support teams would therefore be included in the database.

Data Collection for the database

There are numerous collection forms utilized by the nutrition support teams to acquire data for the electronic PN database. Designated clinical and departmental staff has been granted access to enter data in the database as per IRB approved guidelines and a security table is in place to activate or inactivate personnel who access it. Data is additionally secured by a 96 hour lockout after entry, which is permanent and cannot be altered.

Extracted data include: Demographic, anthropometric, diagnoses and anatomical information as well as PN related information such as rationale, treatment plan, dietary intake (if allowed), laboratory values, radiologic studies, operative report,

intake and output records and PN component and infusion details; patient phone calls and notes are a part of the data that is collected. PN episodes which includes the therapy start and end dates as well as the reason for stopping the infusions and the intended plan for PN therapy is indicated as less or greater than six months are also collected. In addition, hospital readmissions within 30 days, home PN related readmissions, the incidence of complications such as catheter related blood stream infections (CRBSIs) and dehydration and the reason for ending PN. Furthermore, inpatient nutrition support team nurse interventions including patient and family education and management of central line catheter needs are being documented. Outpatient visits with NST clinicians and physicians as well as home care and infusion agencies providing services are also tracked.

Current Study

This study will examine context, process and outcome factors and self-management behaviors of persons on home parenteral nutrition and their families with Ryan and Sawin's (2009, 2013) middle-range Individual and family self-management theory as the guiding framework. The model consists of context, process, and outcome dimensions. Independent variables emanate from the factors of each dimension. Factors of the context dimension are grouped into condition specific, physical and social environment and individual and family factors. Condition specific variables for this study are: rationale for PN use and duration of home PN therapy. The physical factor variable is the individual's geographical location and individual and family factors are comprised of the demographic variables.

The process dimension is comprised of three concepts or factors – knowledge, individual and family self-management behaviors and social facilitation. Educational model used during PN instruction, engagement in the care regimen and family and caregiver support are the variables to be measured in this dimension. The outcome dimension of the IFSMT model is divided into proximal and distal factors which are the dependent variables. The proximal outcome is engagement in care and the distal outcome is acute care readmission.

Design

This study was quantitative, exploratory, retrospective analysis of an existing dataset investigation. Data were extracted from source data for analysis to address the research questions of this study.

Sample and Setting

The sample consisted of adults who were new to home parenteral nutrition from, January, 2013 through December 1, 2013, that were being managed by the nutrition support teams at a 1000-bed Midwestern academic medical center. The sample was selected from the IRB approved home PN database maintained by the nutrition support teams. Individuals selected had to be on parenteral nutrition at home or temporarily inpatient for a specific issue such as management and treatment of a complication or problem.

Inclusion criteria

Any person who was on home PN for 30 days or greater within 2013 was included in this study. The 30 day time frame was established because the standard of

care is that post-acute NST clinic visits are scheduled one month after discharge so a person would have needed to be on home PN 30 days in order to meet the requirements of the Engagement independent variable of the study. The standard of care in this institution is that first time PN therapy is initiated in the hospital setting.

Exclusion criteria

Individuals who were managed by the home PN team but receiving IV fluids only, were excluded from the sample as were individuals who were new to the medical center for management of their care, but who had previously received home PN through another hospital or institution. Patients who had been prescribed PN but were discharged to skilled nursing facilities, acute rehabilitation or long term acute care facilities were also not included in this study.

Power Analysis

“The power of a statistical test is the proportion of the distribution of test statistics expected for a study (based on the sample size and the estimated effect size) that is above the critical value used to establish statistical significance” (Murphy, Myors & Woloch, 2009, p.14. Power can also be described as the ability to detect a difference in treatment when an effect has occurred and is designated as 1- Beta (β). G*Power version 3.1.3, a power analysis software program was used to calculate the minimum sample size needed.

Power in this study was set at .80 with a medium effect size and a level of significance of .05 with 6 independent predictor variables for logistic regression analysis, which required a sample of about 100 in order to have adequate power (Faul, Erdfelder, Lang & Buchner, 2007).

Analysis of an Existing Dataset

Analysis of an existing dataset and secondary data analysis are research methods that permit the scientist to re-examine existing data for another purpose (LoBiondo-Wood & Haber, 2010). There are many benefits to utilizing an existing database. Data have been previously gathered so time and expense related to an extensive investigation is avoided (Schlomer & Copp, 2013; Grady & Hearst, 2007). Furthermore, resources that would have been spent on data collection can be used on other facets of the study (Magee, Lee, Giuliano & Munro, 2006). Secondary data analysis can also be helpful in assessing trends, patterns and outcomes of medical treatments (Grady & Hearst, 2007) as compared to the original study data. In addition, nursing knowledge development can occur as new findings are produced from newly investigated research questions (Gleit & Graham, 1989; Magee et al., 2006). Schlomer & Copp (2013) comment that studies using existing databases may permit more thorough examination of research questions than could not be explored by other methods.

Threats to internal and external validity may be a concern with this method if certain data were not collected and accuracy of the findings may be questioned if available data does not adequately address the research questions. External validity is impacted if results are less generalizable to the population (Magee et al., 2006). Special attention should be paid to interpretation and data analysis to be sure that results are not over-inflated especially in large datasets where large samples may favor significant findings that may indeed not be as significant as indicated thus a Type I error is committed (Magee et al., 2006).

Measures

Context variables

Variables from the context dimension of interest were gender, age, race/ethnicity, and insurance provider which are documented per self-report unless otherwise indicated. In addition, geographic location as determined by addresses and zip codes was obtained as these provided a better understanding if differences in outcomes according to residence in urban, urban cluster or rural communities were found.

Gender was documented as either male or female. The chronological age was calculated based on the years of life at the initiation of PN therapy. Race/ethnicity was described as: White, Black, Hispanic, Asian, Arab and Other. Insurance provider was categorized as commercial, or private pay – when an individual paid for their care independent of insurance means and Medicare, Medicaid, dual eligible and uninsured.

It was important to know if accessibility to health providers was a factor in home parenteral management because subjects receiving care in this sample came from all three community types: urban (population of 50,000 or more), urban cluster (population of 2,500 to 49,999) or rural (population less than 2,500). The geographic location was measured according to the population size of the city or township where patients reside.

The Health Resources and Services Administration (HRSA) manages the Health Professional Shortage Area (HPSA) Index which provide numerous data regarding accessibility to health care (Health Resources and Services Administration, 2014; Smith et al., 2013). There are three HPSA designations: Primary health care, dental and mental health but for the purposes of this study, only the primary health care HPSAs

will be analyzed. When the primary health care HPSA ratio indicates there is less than one health care professional for 3,500 people, it is considered a designated HPSA. The subject's address, city and zip code and county (if needed) were entered into the HPSA database to determine residence in a primary care health professional shortage area. HPSAs are scored (range is from 1 – 25) according to the severity of shortage with larger numbers indicating a greater need (HRSA, 2014). Therefore, residence in an HPSA and the accompanying priority of need score were measured to more fully describe the characteristics of the sample.

Independent Variables

The independent variables for this study from the context dimension are: PN rationale, duration of PN and family and caregiver support. Educational model employed for PN lessons is a process dimension variable. The PN rationales were indications for the use of the therapy and were grouped into four categories: short bowel syndrome and malabsorption, obstruction and ileus, fistula and perforation, and other. The HPN episode in the database provides length of therapy in days in addition to other measurements. PN duration was the number of days in 2013 that the subject was prescribed the therapy.

Lessons for managing care at home are critical and provided to every individual and their family member or primary caregiver prior to hospital discharge. The three educational models measured consisted of nurse-led individual lessons, group lessons or a combination of both types of classes that occurred in the hospital prior to discharge.

The family and caregiver support variable described the unpaid person(s) assisting the individual in the care and management of PN therapy described

specifically as spouse, parent, sibling, significant other, child, other relative or friend. Three categories were established to identify those responsible for caregiving. Subjects who considered themselves primarily responsible for their own care were classified as primary caregivers; subjects, and unpaid family members and friends agreeing to shared caregiving were measured; and lastly unpaid family members or friends who as individuals managed the caregiving were noted as well.

Dependent Variables

The proximal outcome variable, engagement, and the distal outcome variable acute care readmission were the dependent variables. Engagement in self-management of the health care regimen was operationalized as active participation in health care tasks necessary for safe effective care; maintaining communication regarding health status changes or problems via, telephone, fax or email correspondence as well as seeking collaboration with health care providers managing their care.

To determine the characteristics encompassed within engagement, a review of the literature was conducted to determine the evidence-based concepts included in other models attempting to quantify engagement. Key concepts derived from this examination were: communication, collaboration, commitment, activation and empowerment. An informal survey was conducted among the physicians and clinician experts of the Nutrition Support Teams (NST) to inquire about factors they felt were important in defining a patient's engagement in their care. Instruments measuring engagement or activation – a component of engagement, in care of individuals on PN therapy or their caregivers were not found in the literature. The factors identified by the NST that were felt to be indicative of engagement were: Keeping clinic visit appointments with NST

health care providers which included physicians, nurse practitioners and dieticians; submitting weight, glucose values and intake and output reports to the NST and communicating contact information along with any changes in routine, development of symptoms or hospitalizations. The total number of activities maintained during PN therapy was tallied and recorded for each subject. It is also noted that every patient whose care is managed by the NST is presented with an agreement that outlines responsibilities and care routines deemed to be necessary for safe administration of the therapy at home and all of the factors the team identified as important are listed in this agreement.

Acute care readmission was the distal outcome and dependent variable. Any readmission occurring during the time the subject was on home PN therapy was measured. Reasons for readmission were described as PN related and thus would be due to complications such as CRBSIs or dehydration or non-PN related causes, for example, a scheduled procedure or surgery will be discussed in the analysis.

Descriptive Context characteristics

Other context descriptive data that were examined to more fully understand the characteristics of the sample include: state of residence, presence and type of post-acute contact with health providers exclusive of NST and home care services, presence of an ostomy or fistula, mode of contact with NST measured as phone, fax, email or a combination of these options.

Procedures

The parenteral nutrition database is not open to the public therefore access is restricted to persons approved according to the medical center institutional review board

(IRB) guidelines for this database. As a requirement for conducting research at the medical center, completion of designated procedures was necessary before a study can be initiated. According to policy, all nurses conducting research are provided a research mentor from the medical center nursing research institute whose role is to oversee the conduct of research and serve as a resource during the investigative process. The researcher was required to complete and successfully pass, a series of research self-study modules required by the medical center nursing research institute before the research proposal could be submitted to the IRB. Current Collaborative Institutional Training Institute (CITI) certification as approved by the Continuing Research Education Credit (CREC) program of the academic institution was verified and accepted through a reciprocal agreement with the medical center before forwarding the proposal to the IRB.

The researcher applied to the (IRB) using the medical center intranet web kit with the assistance of the research mentor. Once approval was granted by the IRB, the researcher was able to gain access to the PN database, electronic health record, and HPSA index and nurse educational records.

Subjects were accessed from source data extracted from the IRB approved 5096 registry: Home total parenteral nutrition database by the digestive disease institute database manager who was given a list of the variables of the study by the researcher after IRB approval of the study was granted. Data were deposited into a secure, password protected software program - JTool by the database manager. The researcher was granted access after IRB approval was obtained and data were downloaded into the dataset. Data were also extracted from the electronic health record and the educational

records of patient and caregiver lessons provided by the NST nurses. Data not directly downloaded into the dataset from JTool was gathered on IRB approved and stamped data collection forms and entered into the dataset categorized by the study variables. The inclusion and exclusion criterion were applied to obtain the final sample.

Data Management

Unique identifiers were assigned to each subject and protected health information was deleted from the dataset after numerical coding was complete according to the codebook criteria.

Continuous, categorical or nominal, ordinal as well as dichotomous data were coded for analysis of this sample. The context dimension categorical variables: gender, race/ethnicity, geographic location, HPSA residence, insurance provided, PN rationale, family caregiver support; process dimension variable, educational model; proximal outcome variable, individual and family engagement in care; and, distal outcome variable, acute care readmission were all numerically coded, but were analyzed at a nominal level. Continuous variables were analyzed as extracted with one exception – descriptive groupings of age and duration of PN therapy were completed to distinguish cohort differences. Frequencies were run for all variables to confirm that data were properly coded and missing data were identified.

The master list of subjects is stored separately on a secure server at the medical center. Data collection forms are stored in a locked cabinet in a locked office at the medical center and will be maintained until the study is published. The dataset will be stored within the secure, password-protected servers also at the medical center, that are routinely backed-up by the information technology department to be accessed by a

password-protected desktop computer at the medical center. The Primary Investigator, Co-Investigators, research mentor and those designated in the IRB approval document may have access to the data via desktop computer only as necessary. A back-up of the dataset is stored on an encrypted jump drive and questionnaires used to gather the extracted data are kept in separate secure location at the medical center. Missing values were found for one variable and were coded “99” so they were more readily identifiable.

Data screening and cleaning

Data screening included running frequencies to detect missing data and influential cases for categorical and continuous variables. Continuous variables were further assessed with measures of central tendency including skewness and kurtosis to determine if they are normally distributed. Multiple linear regression was used to test for multicollinearity of the predictor variables to assure that variables were not too closely correlated. Cook’s distance was used to assess for independent and dependent variable influential cases and the Mahalanobis distance which measures the distance from the mean of the predictors to the potential influential case (Field, 2009), was used to test the independent variables for influential cases.

Additional data screening included testing the assumptions for the appropriate statistical test to assess for any violations. No violations were discovered in the data screening process.

Data Analysis

The International Business Machine (IBM) Statistical Product and Service Solutions Software (SPSS) version 22.0 was used for data analysis.

Research Questions:

1. What are the context dimension characteristics (gender, race/ethnicity, age, geographic location, insurance provider, residence in a HPSA, PN rationale, PN duration, family/caregiver support) of individuals and families managing home PN in this sample?

Univariate analysis - Descriptive statistics including mean, median and standard deviation, group size and percentage were used to analyze the relationships of the variables of the context dimension.

2. What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the proximal outcome variable, individual and family engagement in care?

Chi-square bivariate analysis, multivariate logistic regression and multivariate linear regression.

3. What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the distal outcome variable, acute care readmission?

Chi-square bivariate analysis, multivariate logistic regression and multivariate linear regression.

4. What is the relationship between the process dimension factor, type of educational model utilized, and the proximal outcome variable, individual and family engagement in care?

Chi-square bivariate analysis, multivariate logistic regression and multivariate linear regression.

5. What is the relationship between the proximal outcome variable individual and family engagement in care and the distal outcome variable acute care readmission?

Chi-square bivariate analysis, multivariate logistic regression and multivariate linear regression

Assumptions of Chi-Square

Chi-Square test is used to analyze categorical or ordinal data. Chi-square for contingency tables can be used to evaluate more than one sample, whereas Chi-square for association involves a comparison of groups from the same sample (Corty, 2007).

1. Data in cells should be frequencies as opposed to percentages.
2. Levels of categories of the variable must be mutually exclusive so that data only fit into one category.
3. The value of the cells should number 5 or more in at least 80% of the cells.

(McHugh, 2013)

Assumptions of Logistic Regression

Logistic Regression is a means of analyzing dichotomous outcome variables and classifies them according to groups (Mertler & Vannetta, 2010). The independent variables can be continuous, categorical or dichotomous and assumptions regarding

linearity, central tendency and normal distribution of independent variables do not have to be met with Logistic regression (Mertler & Vannetta, 2010).

1. There must be adequate variance of the independent variables.
2. There should not be influential cases that impact the regression.
3. There should not be multicollinearity among the variables.
4. Any missing variables must be missing completely at random.

(Mertler & Vannetta, 2010; Burant, 2014)

Odds ratios are reported in logistic regression and they represent the effect that the independent variable has on the dichotomous outcomes (Mertler & Vannatta, 2010). The odds ratio determines the likelihood of being classified in one or another category of the dichotomous variable. The goodness of fit is determined by the classification tables of the model before and after entry of the variables into the model and it is necessary to determine the final model.

Multiple linear regression was used to examine if there was multicollinearity of variables and to assess for outliers, otherwise both outcome variables were dichotomous and were analyzed using logistic regression.

Human Subjects

Data extraction did not proceed until approval was obtained from Dissertation committee chair, the assigned Medical center nursing research institute mentor and the Institutional Review Board (IRB) and Sub-Investigator status had been granted.

As a part of their responsibility in evaluating potential studies, the IRB is expected to assign a level of anticipated risk to each investigation. It is anticipated that

this study would be categorized as having minimal risk research, which is defined as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests”, as written in the Code of Federal Regulations (2009).

The dataset was created and stored securely and was available only to the Responsible Investigator, Co-Investigator and designees as indicated in the IRB approval document. The Responsible Investigator and Co-Investigator had current, appropriate research Compliance certifications on file and assured that active status was maintained throughout the course of the study.

Each subject’s personal identifiable information was coded and names were kept separately from data. Participants were not be identifiable directly or through identifiers. Every attempt was made to assure that privacy and confidentiality were not breached in any way.

Data were securely retained through analysis and publication of the results to prohibit future use by external investigators. This study involved the use existing data and was exempt from full IRB review because there would be no interactions with patients or their families through the use of questionnaires or phone contact, thus an expedited review was requested.

Summary

This chapter reviewed the design, sample, setting, operational definitions, data management and processes for analyzing data for this study. The research questions

posed aimed to offer new insight into the characteristics of the people and their families managing this therapy through the theoretical framework.

Chapter 4

Results and Discussion

The purpose of this exploratory, descriptive retrospective analysis of an existing data set was to examine the Individual and Family Self-Management Theory (IFSMT) and the relationships among the context and process factors and proximal and distal outcomes among adults on home parenteral nutrition (PN) and their families. This chapter describes the sample context, process and proximal and distal outcome characteristics as well as the results of the study.

Results

Description of Sample

There were 269 people who initiated home parenteral therapy with the nutrition support teams in 2013. Of those, 23 patients were prescribed IV fluids only and thus were eliminated from the sample. Forty-eight individuals were receiving PN therapy managed by NST for the first time, but had previously received PN at other institutions and were subsequently removed from the analysis. Lastly, 78 people were prescribed PN that was discontinued less than 30 days from initiation leaving a final sample of 120 subjects.

Research Question 1: What are the context dimension characteristics (gender, race/ethnicity, age, geographic location, insurance provider, residence in a HPSA, PN rationale, PN duration, family/caregiver support) of individuals and families managing home PN in this sample?

The sample consisted of 53 males and 67 females who ranged in age from 20 years to 84 years of age with a mean of 50.6 and SD of ± 15.6 and a median of 51.00. The other variables of the context dimension: race/ethnicity, age, geographic location, residence in a Health Provider Shortage Area, Insurance provider, PN rationale, PN duration and family/caregiver are described next.

Table 4.1 Context Dimension Independent Variables

	N	n (%)	Mean (SD)	Median
Gender	120			
Male		53 (44.2)		
Female		67 (55.8)		
Race/Ethnicity	117			
White		100 (83.3)		
Non-white		16 (13.7)		
Missing		3 (2.5)		
Age	120		50.63 (15.56)	51.00
Geographic Location	120			
Non-rural		103 (85.8)		
Rural		17 (14.2)		
Resides in Health Professional Shortage Area (HPSA)	120			
Yes		26 (21.7)		
No		94 (78.3)		
Insurance Provider	120			
Commercial-Private pay		78 (65.0)		
Medicare - Medicaid				
Dual eligible- Uninsured		42 (35.0)		
PN Rationale	120			
SBS-Malabsorption		45 (37.5)		
Obstruction – Ileus		31 (25.8)		
Fistula – Perforation		23 (19.2)		
Other		21 (17.5)		
PN Duration – Length of Time on Therapy	120		100.6 (72.4)	73.50
Social Capital- Family/ Caregiver Support	120			
Patient primary		21 (17.5)		
Unpaid family/ caregiver		68 (56.7)		
Shared caregiving		31 (25.8)		

Table 4.2 Family/friend unpaid caregivers

	N	n (%)
Individuals	68	
Spouse		37 (54.4)
Parent		13 (19.1)
Child		8 (11.8)
Significant other		4 (5.9)
Other relative		3 (4.4)
Sibling		2 (2.9)
Friend		1 (1.5)

Table 4.3 Shared unpaid caregivers

	N	n (%)
Pairs	31	
Subject – Spouse		10 (32.3)
Subject – Parent		5 (16.1)
Spouse – Parent		3 (9.5)
Subject – Child		2 (6.5)
Subject – Other relative		2 (6.5)
Parent – Significant other		2 (6.5)
Spouse – Child		2 (6.5)
Spouse – Sibling		2 (6.5)
Subject – Sibling		1 (3.2)
Child – Other relative		1 (3.2)
Significant other – Sibling		1 (3.2)

Descriptive Context Characteristics of other factors related to home PN

Post-acute hospital care was examined descriptively to supplement interpretation and provide for more comprehensive analysis of the sample. All subjects were active with home care and home infusion agencies but these visits were not included in the visit total. Outpatient clinic visits with NST clinicians were captured as activities measured in the engagement variable and thus were not included in these totals either.

The number of subjects who had physician/practitioner, emergency room or an observation stay in a hospital or a combination of these providers numbered 111 or 92.5% leaving only 9 subjects or 7.5% who did not have post-acute health care contact beyond NST and home care visits while receiving PN. The number of subject visits to providers ranged from 1 to 20 while on therapy.

The most common primary diagnoses of the sample were cancer, n=29 (24.2%) Crohn's disease n=27 (22.5%); and ulcerative colitis n=6 (5%). Of those with cancer as the primary diagnosis, 7 subjects (5.8%) had colon cancer, which was the highest frequency noted. Other cancers included: appendiceal, bladder, breast, cervical, esophageal, gastric, endometrial, ovarian, pancreatic, peritoneal, rectal and renal.

Fifty subjects (41.67%) had ostomies and 70 (58.33%) did not. Of those with ostomies, 26 (52%) had an ileostomy, 12 (24%) had a jejunostomy, 1 (2%) had a duodenostomy, and 4 (8.0%) had a colostomy. The remaining 7 (14%) subjects had 2 ostomies from a combination of those just listed or an ostomy and an ileal conduit. There were 21 subjects (17.5%) that had 1 or more fistula(s) and 99 subjects (82.5%) did not have a fistula. Sixteen subjects (76.2%) had 1 or more enterocutaneous fistula(s); other types of fistulas noted were: 1 subject (4.76%) had enteroenteric, 1 (4.76%) enterovaginal, 1 (4.76%) enterovesicular, 1 (4.76%), mucous, and lastly, 1 (4.76%) was non-specified.

Table 4.4 Descriptive Context Dimension Characteristics

	N	n (%)
Post-acute care contacts	120	
Yes		111 (92.5)
No		9 (7.5)
Number of Post-acute health provider contacts	111	
1		18 (16.2)
2		22 (19.8)
3		10 (9.0)
4		15 (13.5)
5		5 (4.5)
6		9 (8.1)
7		6 (5.5)
8		2 (1.8)
9		7 (6.3)
≥ 10		17 (15.3)
Type of post-acute contact	111	
Emergency Room (ER)		12 (10.8)
Physician visits		79 (71.2)
Physician and ER		17 (15.3)
Observation stays and ER		3 (2.7)
Ostomy present	120	
Yes		50 (41.7)
No		70 (58.3)
Fistula present	120	
Yes		21 (17.5)
No		99 (82.5)

Research Question 2: What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in an HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the proximal outcome variable, individual and family engagement in care?

Frequencies were analyzed for all variables and measures for central tendency were examined for the continuous variables age and PN duration and both were normally distributed. Prior to examining the relationships of the predictors and the proximal outcome variable individual and family engagement, dummy variables were created from the original PN rationale variable to increase the amount of explained variance. The SPSS transform and recode commands were used to create the dummy variables thus identifying the presence or absence of the condition with each case using the values 1=presence of the condition and 0=absence of the condition for each created variable: SBS/malabsorption, fistula/perforation, obstruction/ileus and other. The obstruction/ileus variable was used the reference group for analysis of the other three created dummy variables.

A bivariate analysis using the Chi-square test of associations was conducted to determine the relationships of the context dimension categorical variables (gender, race/ethnicity, geographic location, insurance provider, residence in a HPSA, SBS/malabsorption, obstruction/ileus, fistula/perforation, other and family/caregiver support) and the proximal outcome dependent variable, individual and family engagement in care, (fully engaged or not fully engaged).

Table 4.5 Bivariate Analysis of Engagement in care

Variable	N	Overall (N=120)		Fully Engaged (n=64)		Not Fully Engaged (n=56)		p- value
		Summary	n	Summary	n	Summary	n	
Gender	120		64		56			0.052^a
Male		53 (44.2)		23 (35.9)		30 (53.6)		
Female		67 (55.8)		41 (64.1)		26 (46.6)		
Race/Ethnicity	117		63		54			0.20 ^a
White		101 (86.3)		52 (82.5)		49 (90.7)		
Non-white		16 (13.7)		11 (17.5)		5 (9.3)		
Age	120	50.6 ± 15.6						0.19 ^b
Geographic Location	120		46		74			0.033^a
Rural		17 (14.2)		5 (10.9)		12 (16.2)		
Non-rural		103 (85.8)		41 (89.1)		62 (83.8)		
Resides in a HPSA	120		64		56			0.62 ^a
Yes		25 (20.8)		15 (23.4)		11 (19.6)		
No		95 (79.2)		49 (76.6)		45 (80.4)		
Insurance Provider	120		64		56			0.59 ^a
Commercial– Private Pay		78 (65.0)		43 (67.2)		35 (62.5)		
Medicare– Medicaid Dual Eligible– Uninsured		42 (35.0)		21 (32.8)		21 (37.5)		

Note: p-values: a=Chi square, b=Logistic regression

Table 4.5 (continued) – Bivariate analysis of Engagement in Care

Variable	N	Overall	Fully Engaged	Not Fully Engaged	p value	
		(N=120)	(N=64)	(N=56)		
		Summary	n	Summary	n	Summary
PN Rationale	120		64		56	
SBS/malabsorption		45 (37.5)		30 (46.9)		15 (26.8)
Obstruction/Ileus		31 (25.8)		11 (17.2)		20 (35.7)
Fistula/Perforation		23 (19.2)		11 (17.2)		12 (21.4)
Other		21 (17.5)		12 (18.8)		9 (16.1)
PN Duration (days)	120	100.6 ±72.4				
Educational Model	120		64		56	0.061 ^a
Individual		117 (97.5)		64 (100.0)		53 (94.6)
Group		3 (2.5)		0 (0.0)		3 (5.4)
Family/caregiver Support	120		64		56	0.54 ^a
Patient primary caregiver		21 (17.5)		9 (14.1)		12 (21.4)
Individual caregiver		68 (56.7)		37 (57.8)		31 (55.4)
Shared caregiving		31 (25.8)		18 (28.1)		13 (23.2)
Acute Care Readmission	120		64		56	0.84 ^a
Not Readmitted		46 (38.3)		24 (37.5)		22 (39.3)
Readmitted		74 (61.7)		40 (62.5)		34 (60.7)

Note: p-values: a=Chi square, b=Logistic regression

Gender was non-significant but trending toward it: $\chi^2 = 3.766$, 1 *df*, $p = .052$. Significant variables were geographic location (rural or non-rural): $\chi^2 = 4.554$, 1 *df*, $p < .033$, and the PN rationale, SBS/malabsorption: $\chi^2 = 5.143$, 1 *df*, $p < .023$. The additional recoded dummy variables examined were fistula/perforation: $\chi^2 = .342$, 1 *df*,

$p = .556$, and other: $\chi^2 = 5.351$, 1 *df*, $p < .021$. Obstruction/ileus was the reference group.

The continuous variables age and PN duration were analyzed in a logistic regression to determine the relationship with the engagement, prior to entry into the regression with other variables. The logistic regression analysis revealed: The -2 Log likelihood = 164.076, $\chi^2 (1) = 1.746$, $p = .186$. The unadjusted odds ratio for age and engagement (fully engaged and not fully engaged) is as follows: (OR = 1.016, 95% CI .992 – 1.040, $p = .190$), which indicates there was not a significant relationship with individual and family engagement in care. The logistic regression analysis for PN duration and engagement -2 Log likelihood = 152.107, $\chi^2 (1) = 13.715$, $p < .000$, and the unadjusted odds ratio for PN duration and engagement was: (OR = .989, 95% CI .982 - .996, $p < .001$) signifying there was a significant relationship.

As a part of the data cleaning process, the variables were examined for influential cases and multicollinearity using multiple linear regression, which is recommended by Mertler & Vannetta (2010) and presence of either would be a violation of the assumptions for logistic regression. No multicollinearity was found for any of the predictor variables as indicated by Tolerance index values that were greater than 0.1.

The Cook's distance was used to assess for outliers of both the predictors and dependent variables and all values were less than 1.0, which indicates there were no outliers that significantly impacted the regression. The Mahalanobis analysis, which tests for outliers of the predictor variable by measuring the distance from the mean of

the predictors to the potential influential case (Field, 2009) was also negative for any outliers.

The context dimension variables gender, age, geographic location, PN duration and the PN rationale dummy created variables: SBS/malabsorption, fistula/perforation and, other (comparison dummy variable was obstruction/ileus) were entered into the logistic regression by the simultaneous or enter method to determine which of these variables were predictive of the proximal outcome variable, individual and family engagement in care (fully engaged or not fully engaged).

Table 4.6 Logistic Regression Model for Engagement in Care

Variable	Sig.	Exp (B)	95% CI for Exp (B)	
			Lower	Upper
Gender	.041	2.456	1.037	5.817
Age	.138	.980	.954	1.007
Geographic Location				
Non-Rural	.017	4.715	1.315	16.907
SBS-Malabsorption	.005	5.022	1.618	15.589
Fistula/Perforation	.064	3.352	.934	12.035
Other	.068	3.367	.912	12.427
PN Duration	.001	1.012	1.005	1.020

The regression results indicated that the overall model of four predictors: gender, geographic location – rural or non-rural, SBS/malabsorption as compared to obstruction/ileus and PN duration was reliable statistically in distinguishing between being fully engaged or not fully engaged. The -2 Log likelihood =133.019, $\chi^2 (7) = 32.802$, $p < .000$. The model correctly predicted 70.0 percent of the cases (initial block 53.3 percent). The Nagelkerke R square estimates that 32% of the variance in the dependent outcome variable was explained by the model. The Hosmer and Lemeshow

test is based on Chi-square and the hypothesis that the data don't fit the model (Burant, 2013) so the value should be greater than the $p < 0.05$ value and in this case it was .246 which is non-significant indicating that this is a good-fitting model.

Odds ratios:

Females were 2.5 times more likely to be fully engaged as compared to males. (OR= 2.456, 95% CI 1.037 – 5.817, $p < .041$).

Individuals who lived in non-rural areas were 4.7 times more likely to be fully engaged as compared to those who lived in rural areas. (OR = 4.715, 95% CI 1.315 - 16.907, $p < .017$).

Subjects with SBS/malabsorption were 5 times more likely to be fully engaged as compared to those with obstruction/ileus. (OR=5.022, 95% CI 1.618 - 15.589, $p < .005$)

For every additional day on home PN therapy, the odds of being fully engaged increased by 1%. (OR= 1.012, 95% CI 1.005 - 1.020, $p < .001$)

Research Question 3: What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in an HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the distal outcome variable, acute care readmission?

The data cleaning process described previously applies to this analysis as well and no influential cases were noted with the acute readmission variable. The dummy variables created from the original variable, PN rationale: SBS/malabsorption, obstruction/ileus, fistula/perforation and other were again used to provide for more

explained variance prior to testing Chi-square. Fistula/perforation was used as the reference group.

Bivariate analysis was conducted using the Chi-square test of associations to examine if there were significant relationships among the categorical context dimension variables (gender, race/ethnicity, geographic location, residence in a HPSA, insurance provider, PN rationales: SBS/malabsorption, obstruction/ileus, fistula/perforation and other and family/caregiver support) and the distal outcome dependent variable, acute care readmission (yes or no).

Table 4.7 – Bivariate analysis of Acute care readmission

Variable	N	Overall	No Acute care Readmission		Acute care Readmission		p-value
		(N=120)	n	Summary	n	Summary	
Gender	120		46		74		0.21 ^a
Male		53 (44.2)		17 (37.0)		36 (48.6)	
Female		67 (55.8)		29 (63.0)		38 (51.5)	
Race/Ethnicity	117		44		73		0.27 ^a
White		101 (86.3)		36 (81.8)		65 (89.0)	
Non-white		16 (13.7)		8 (18.2)		8 (11.0)	
Age	120	50.6 ± 15.6					0.34 ^b
Geographic Location	120		46		74		0.591 ^a
Rural		17 (14.2)		5 (10.9)		12 (16.2)	
Non-rural		103 (85.8)		41 (89.1)		62 (83.8)	
Resides in HPSA	120		46		74		0.165 ^a
Yes		25 (20.8)		13 (28.3)		12 (16.2)	
No		95 (79.2)		33 (71.7)		62 (83.8)	
Insurance Provider	120		46		74		0.97 ^a
Commercial, Private Pay		78 (65.0)		30 (65.2)		48 (64.9)	
Medicare, Medicaid, Dual Eligible, Uninsured		42 (35.0)		16 (34.8)		26 (35.1)	

Note: p-value: a=Chi square, b=Logistic regression

Table 4.7 (continued) – Bivariate analysis of Acute care readmission

Variable	N	Overall	No Acute	Acute	p-value
		(N=120)	Care Readmission (n=46)	Care Readmission (n=74)	
		Summary	n	Summary	n
PN Rationale	120		46		74
SBS /malabsorption		45 (37.5)		10 (21.7)	35 (47.3)
Obstruction/ Ileus		31 (25.8)		11 (23.9)	20 (27.0)
Fistula/ Perforation		23 (19.2)		12 (26.1)	11 (14.9)
Other		21 (17.5)		13 (28.3)	8 (10.8)
PN Duration (days)	120	100.6±72.4	46		74
Educational Model	120		46		74
Individual		117 (97.5)		43(93.5)	74 (100.0)
Group		3 (2.5)		3 (6.5)	0 (0.0)
Engagement	120		46		74
Fully engaged		64 (53.3)		24 (52.2)	40 (54.1)
Not fully engaged		56 (46.7)		22 (47.8)	34 (45.9)
Family/Caregiver	120		46		74
Support					
Patient primary		21 (17.5)		11 (23.9)	10 (13.5)
caregiver					
Individual		68 (56.7)		23 (50.0)	45 (60.8)
caregiver					
Shared caregiving		31 (25.8)		12 (26.1)	19 (25.7)

Note: p-value: a=Chi square, b=Logistic regression

Chi-square analysis results were: Gender: $\chi^2= 1.573$, 1 *df*, $p=.210$, geographic location: $\chi^2= .667$, 1 *df*, $p= .414$, SBS/malabsorption was shown to be significant: $\chi^2= 7.906$, 1 *df*, $p< .005$ as was the “other”: $\chi^2= 5.983$, 1 *df*, $p< .014$; and the fistula/perforation chi-square analysis was: $\chi^2= 5.351$, 1 *df*, $p =.129$.

The continuous context dimension variables, age and PN duration were examined by logistic regression to determine the relationship with the dichotomous distal outcome dependent variable, acute care readmission. The logistic regression analysis for age and acute care readmission was as follows: -2 log likelihood = 158.839, $\chi^2 (1) = .922$, $p=.337$. The unadjusted odds ratio for age and acute care readmission was: (OR = 1.012, 95% CI .988 - 1.036, $p =.339$) thus there was not a significant relationship with these variables. Lastly, PN duration and acute care readmission were examined with the following results: -2 log likelihood = 156.272, $\chi^2 (1) = .3489$, $p = .062$. The unadjusted odds ratio for PN duration and acute care readmission was (OR = 1.005, 95% CI, .999 – 1.011, $p=.078$). Neither of these variables revealed a significant relationship with acute care readmission, although, PN duration was trending in that direction.

The variables gender, age, geographic location, SBS/malabsorption, fistula/perforation, other and PN duration were entered into the model at one time using the simultaneous or enter method. The logistic regression demonstrated that there were no significant relationships among the context variables and the distal outcome variable, acute care readmission. The -2 log likelihood =141.485, $\chi^2 (7) = 18.276$, $p =.011$, The Nagelkerke R square indicated that the model accounted for 19.2 percent of the variance. The Hosmer and Lemeshow index was non-significant at $p = .394$.

Table 4.8 Logistic Regression Model for Acute care readmission

Variable	Sig.	Exp (B)	95% CI for Exp (B)	
			Lower	Upper
Gender	.178	.567	.249	1.293
Age	.322	1.013	.987	1.041
Geographic Location				
Non-Rural	.273	.512	.155	1.695
SBS-Malabsorption	.299	1.742	.611	4.962
Fistula/Perforation	.174	.174	.934	1.426
Other	.063	.322	.098	1.061
PN Duration	.130	1.005	.999	1.011

Research Question 4: What is the relationship between the process dimension variable, type of educational model utilized, and the proximal outcome variable, individual and family engagement in care?

Frequencies of the educational model variable were analyzed and it was determined that there was less than 5% variability in the educational model variable, thus it could not be adequately statistically tested. Of the 120 subjects in the sample, only 3 (2.5%) had group lessons and the remainder, n=117 (97.5%) having an individual lesson at the bedside. The bivariate Chi-square analysis was: $\chi^2= 3.516, 1 df, p= .061$.

Table 4.9 Educational Model and Individual and Family Engagement in Care

Educational Model	Fully Engaged		Not Fully Engaged		Total		p-value
	n	%	n	%	n	%	
Group	0		3	(2.5)	3	(2.5)	.061 ^a
Individual	64	(53.3)	53	(44.2)	117	(97.5)	
Combination	0	(0.0)	0	(0.0)	0	(0.0)	
Total	64	(53.3)	56	(46.7)	120	(100.0)	

Note: p-value: a=Chi-square

Research Question 5: What is the relationship between the proximal outcome variable individual and family engagement in care and the distal outcome variable, acute care readmission?

The Chi-Square analysis was: $\chi^2 = .040$, 1 *df*, p value = 0.84 revealed there was no association noted between individual and family engagement in care and acute care readmission.

Table 4.10 Individual and Family Engagement in Care and Acute Care Readmission

	Fully Engaged		Not Fully Engaged		Total		p-value
	n	%	n	%	n	%	
Acute Care Readmission							.084 ^a
No	24	(20.0)	22	(18.3)	46	(38.3)	
Yes	40	(33.3)	34	(28.4)	74	(61.7)	
Total	64	(53.3)	56	(46.7)	120	(100.0)	

Note: p value: a=Chi-square

Discussion

Research Question 1: What are the context dimension characteristics (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, and family/caregiver support) of individuals and families managing home PN in this sample?

The subject's ages spanned from 20 to 84, with a mean of 50.6 years (SD=15.6) and a median of 51.00 years but when examined by cohorts, they were fairly evenly divided: ages 20-39 numbered 35 (29.2%), ages 40-59 numbered 41 (34.2%) with the

largest cohort 44 (36.7%) being those age 60 or older. Howard, Amendt, Fleming, Shike & Steiger (1995) reported the age range for initiation of PN therapy was widening even at that time. In the literature, age is most often described as adult or pediatric with means and standard deviations reported.

The mean age reported in two studies utilizing the home TPN database was: 52.9 (14.2%) in an investigation by deBurgoa et al., (2006) that reported on complications of patients in 2003-2004 managing home PN. John, et al., (2010) explored ethanol lock therapy and CRBSIs in adult home PN patients and had a mean age of 49.4 (11.6%). In another study conducted in the Netherlands to investigate the quality, content and quantity of care provided by health professionals by Huisman-de Waal et al., (2011), the mean age was 53, SD=14.7 with an age range of 18-77. The ages of subjects in the current study is in alignment with what is being reported in the literature. Howard (2006) summarized what was known about health outcomes in the PN population at the time of her writing based on data from the North American home parenteral and enteral nutrition patient registry. She reported PN survival rates according to age at initiation of therapy and categorized age cohorts as: less than 40 years, 40-60 years and greater than 60 years. Those beginning PN at age 60 or older, had higher mortality associated with PN use and Howard hypothesizes that reasons for this may be related to medical fragility and possessing a lack of capacity to tolerate the complexities of intestinal failure even though, overall those in this age-group had good outcomes. The intent in examining age in the current study was to determine the range and to evaluate the relationships with the outcome variables in the study however, there

was not a significant relationship between age and either engagement or acute care readmission.

Subject's race/ethnicity were analyzed as white, n=101 (84.1%) and non-white, n=16 (13.3%) and missing, n=3 (2.5%). No studies were found in the literature that addressed have addressed race and home PN therapy. However a study by Nguyen, Munsell, Brant & LaVeist (2009) investigated race in an inpatient PN population.

Racial and geographic disparities in parenteral nutrition use among patients with inflammatory bowel disease (IBD) – that is, those with Crohn's disease or ulcerative colitis, were reported in a study by Nguyen et al., (2009). Data from the U.S. Nationwide Inpatient Sample database for the years 1998 to 2003 were analyzed. The results indicated that the proportion of subjects with IBD who received PN and were African American was 19.9% as compared to whites (28.1%), $p=.001$. Statistical significance was not noted between Hispanics and whites (22.9% vs 28.1%, $p= .27$). The findings according to the researchers suggests that there may be differences in quality of care among race/ethnicities; malnutrition appears to be identified later in the African American and Hispanic populations accompanied by a delayed initiation in PN therapy; and having decreased access to hospitals with interdisciplinary nutrition support teams may also be a factor in PN being considered an option (Nguyen et al., 2009). The percentages of subjects by race/ethnicity were lower in the current study: white, n=100 (83.2%); black, n= 10 (8.3%); Hispanic, n= 3 (2.5%); Arab, Asian or multiracial, n= 4 (3.3%) and for n= 3 (2.5%) that were missing. Future investigation is essential to provide confirmation or support for other factors contributing to this disparity.

Subjects are from 17 U.S. states/territories and an international location in this database specifically, which accounts for challenges experienced by the nutrition support teams and case managers planning and facilitating PN management transitioning from the hospital to the home environment. The case manager has a pivotal role in facilitating home care and infusion arrangements along with other members of the interdisciplinary team. One hundred three subjects (85.8%) came from urban environments, but there were 17 (14.2%) people from rural areas.

Twenty-five subjects came from areas designated as health professional shortage areas (HPSAs) were found in all three community types - urban, urban cluster and rural in this sample. The Health Resources and Services Administration (HRSA) is an agency of the United States Department of Health and Human Services that is responsible for making health care accessible to those who are uninsured, isolated or medically vulnerable (HRSA, 2014) and Health Professional Shortage Areas (HPSAs) which may be geographic regions, population groups or facilities have been identified to address this need. Federal funding is available to HPSAs and as of June, 2014, there were approximately 6,100 primary care HPSAs in the U.S. (HRSA, 2014). The subject's residence in primary health care HPSAs were analyzed in this study as were the score ratings indicating priority of shortage with higher numbers representing greater needs. The scores from subjects in this sample ranged from 4 to 19 and 2 scores were unattainable. Inadequate numbers of non-white ethnic groups and rural subjects in this sample did not permit comprehensive exploration of these context dimension variables, however, having this information could facilitate identification of

deficiencies in resources and provide support for supplementation of necessary services or supplies related the specific care needs of those on PN therapy.

Understanding and navigating the array of health care benefits and limitations of insurance policies for care as complex as this can be overwhelming to traverse. For example, planning for post-acute care in two locations for the people who live outside of the medical center home state, but choose to stay locally for a time before returning home is not uncommon and can be a daunting task. Having an understanding of where subjects live provides an opening for addressing needs before potential problems arise. It would be valuable to have information regarding insurance products common in a particular state and that could help in negotiating for coverage deficits including transportation needs before admission. The NST has been securing resources in advance of discharge such as outpatient clinics where labs can be locally drawn or partnering with PCPs and nurse practitioners willing to provide care oversight, but this could be expanded based on the information shared here.

There were 21(17.5%) subjects who chose to assume primary responsibility for care of their own PN but 99 (82.5%) people had either a friend, individual family member or a significant other assisting them- it truly is a shared commitment. Family and caregiver support was not significant with either outcome variable, which suggests that readmission and engagement may be more related to the presence or absence of support as opposed to who is assisting the subject, however further investigation is recommended to more fully understand these relationships.

A number of studies mention that unpaid family and friend caregivers partner with individuals on home PN when prescribed (Huisman-de Waal, 2011; Smith, 1991,

Smith, 1994, Smith, 1999, Smith et al., 1997, Smith et al., 2002 and Winkler et al., 2006). Smith (1991) mentioned spouses and a sibling as caregivers, but most don't describe who specifically is in the role as caregiver. Winkler et al., 2006 conducted a review of the impact that technology dependence has on patients and caregivers in home PN care and other conditions. The complexity of caregiving tasks including the intensity of care, social isolation and emotional, physical and financial burden are all addressed and have been documented in the literature with other populations. However, additional exploration and possible qualitative research of individuals and families partnering in self-management of PN is needed.

Nutrition support team management and follow-up of persons on PN therapy hinges on effective communication as reported in the literature (Dreesen, et al. (2014), therefore, it was important to know how subjects and caregivers communicated with the NST, thus the primary mode of contact was measured. Individual and family engagement in care includes the ongoing expectation that clinical parameters, test results and changes in health status are communicated with the team. The primary mode of contact with the nutrition support team was by phone for all subjects. Two subjects used both phone and email.

Descriptive Characteristics of other factors related the PN therapy

Post-hospital health provider contact data were extracted to gain a better sense of extent to which subjects were involved with other care providers. Only 9 (7.5%) people did not have post-acute contact. The 111(92.5%) who did have contact had emergency room and physician visits and observation stays or a combination of these

modalities. The number of contacts ranged from 1 to more than 10 and this is exclusive of the home care nursing visits each subject has.

Not only is the care regimen complex, but the interdisciplinary management of the therapy is as well. These individuals are high utilizers of the health care system for fully justifiable reasons, but the degree of self-management, engagement and commitment to stabilizing or regaining optimum health can be perceived as daunting. Studies addressing post-hospital contact in this population were lacking, but in consideration of the level of contact observed with these subjects, additional research is highly recommended.

The three most frequent primary diagnoses of subjects in this sample were: cancer, Crohn's disease and ulcerative colitis. All three of these diagnoses have been extensively reviewed in the literature. This current sample and another study by deBurgoa, and colleagues (2006), differs from most studies because Crohn's and ulcerative colitis precede cancer in terms of frequency. Factors that may account for the differences in prescribing home PN among patients with cancer should be examined in a future study. The literature also indicates benefits versus risks must be considered for every individual but especially with those in cancer treatment due to some evidence that PN may impact the spread of cancer. Individuals with cancer are known to have good outcomes when the therapy is used for nutritional deficits earlier in the treatment trajectory (Marian & Roberts, 2010), however additional investigation would be beneficial.

Ostomies and fistulas often accompany the conditions that require nutritional supplementation with home PN. For subjects in this study, 50 (41.67%) had ostomies

and 70 (58.3%) did not have an ostomy. There were 22 subjects (18.3%) with 1 or more fistula(s) and 98 subjects (81.67%) did not have a fistula. Individuals with short bowel syndrome may have an ostomy as a temporary intervention when bowel rest is needed or surgical resectomy is pending or it may be a life-long circumstance and PN use is necessary for the short or long term to address nutritional deficits (Materese, O'Keefe, Kandil, Bond, Costa & Abu-Elmagd, 2005; Parekh & Steiger, 2007). Fistulas may result as a complication of surgery or due to injury or inflammation. A study by Lynch, Delaney, Senagore, Connor, Remzi & Fazio (2004) revealed that enterocutaneous fistulae (ECF) were found to occur with Crohn's disease, ulcerative colitis, diverticular disease, carcinoma, in ventral hernia repairs with mesh and other causes. Drainage of the intra-abdominal abscess, PN and surgical intervention were reported to be the most effective options for healing of the fistula. Managing the care of an ostomy or fistula in addition to home PN can be challenging for patients and families and adds to the complexity of caregiving.

Research Question 2: What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and individual and family engagement in care?

The regression results indicated that the model of four predictor variables were statistically reliable in determining full engagement and not being fully engaged. Other results: Females were 2.5 times more likely to be fully engaged as compared to males

and subjects and their families from non-rural areas were 4.7 times more likely to be fully engaged as compared to those who lived in rural areas.

Individuals with SBS/malabsorption, were 5 times more likely to be fully engaged as compared to individuals with obstruction/ileus. The length of time an individual was on PN improved the odds for engagement in care and for each additional day receiving PN the odds for being fully engaged increased by 1%. Full engagement is the desired outcome because it indicates a person is empowered to collaborate, coordinate and communicate with the health professional team mutually in pursuit of the best outcomes.

The literature is lacking in describing individual and family engagement in the home PN population as it is discussed here, particularly with regarding to the relationships comparing engagement based on gender and studies with rural populations. Regarding gender and engagement, however, one survey reported that women, those who were more educated and healthier people, preferred a more active role in healthcare decision making which is a component of engagement. (Levinson, Kao, Kuby & Thisted, 2005)

Smith, Giefer & Bieker (1991) conducted a study in a rural Midwestern county that focused on family members assisting with PN care in the home and did not examine engagement. Smith (1994, 1999) and Smith and colleagues (2002) examined caregiving relationships with care-receivers and the concept of motivation-to-help in the Caregiving effectiveness model. Other studies reported the challenges of technology-dependent adults in the home (Smith et al., 1991; Smith, 1994; Winkler et al., 2006). Studies examining quality of life outcomes have explored the impact of PN on daily life

(Persoon, et al., 2005); problems (Huisman-de Waal, 2006); psychosocial complaints (Huisman-de Waal, 2011); and reactive depression experienced by the patient (Smith, et al., 2003a). In addition, Winkler's (2005) review reported adjustments in lifestyle as it related to PN and the personal responsibilities associated with the care regimen. All of these studies help to articulate the complexities, psychosocial behaviors and the care experiences of patients and caregivers managing home PN. The concept engagement, offers an opportunity to explore individual and family management from a different perspective.

Subjects with short bowel syndrome and malabsorption were found to be more fully engaged than subjects with obstruction or an ileus. SBS and the accompanying malabsorption may initiate from congenital abnormalities and surgical resection (Matarese, et al., 2005). Subjects with SBS and malabsorption numbered 45 or (37.5%) of the sample and of those, 27 subjects or (60%) had Crohn's disease. Perhaps the trials of managing the condition, fosters engagement in care and collaboration and other self-management behaviors in an attempt to maintain an acceptable perceived quality of life, but additional exploration is necessary to expand knowledge in this area.

There was a significant relationship between the length of time on PN and engagement with the likelihood of not being fully engaged decreasing by almost 1% for every additional day on PN therapy. Studies of those on longer term home PN report that patients adjusted to the routine of care and did not report it as a limitation (Winkler et al., 2010), however, engagement was not examined. Malone (2002) investigated individuals who had been on home PN or enteral therapy at least a year at two time points, 3 years apart and found that subjects had a prolonged stable health status over

the course therapy as evidenced by non-significant differences in SF-36 scores at both time points (Malone, 2002). Once again, individual and family engagement in care was not explored, but the trend toward stability may indicate an adjustment to management of care, but more research is needed.

The expectation in today's health care environment is that individuals and their caregivers will be providing care in the home with increasing frequency. To do so effectively, requires a knowledgeable, communicative, collaborative and engaged individual with social support to order the best achieve optimal health outcomes. The results of the current study cannot be generalized to another population and are exploratory, but further refinement of the concept of engagement as it relates to PN therapy through qualitative or prospective study, may provide insight into the factors associated with individual and family engagement in care that support optimal health outcomes.

Research Question 3: What are the relationships between factors of the context dimension (gender, race/ethnicity, age, geographic location, residence in a HPSA, insurance provider, PN rationale, PN duration, family/caregiver support) and the distal outcome variable, acute care readmission?

The aim was to examine additional factors beyond complications such as dehydration and CRBSI that may lead to hospital readmission as reported in the literature, however, there were no context variables that predicted readmission in this sample. The readmission rate for this sample was 61.7% with 74 subjects being readmitted to acute care while on PN therapy. The number of readmissions per

individual ranged from 1 to 7 and on the first readmission 59 (49.2%) had non-PN related reasons for readmission and 15 (12.5%) had PN related reasons.

DeBurgoa and colleagues (2006) reported in a prospective study of 97 new home PN patients experiencing complications related to home PN use. Forty-four complications were reported and 39 or 88.6% of the subjects required either hospital readmission or a visit to the emergency room, the hospital admission rate alone was not reported. CRBSIs accounted for 22 or 50% of the complications experienced (deBurgoa, et al., 2006). Corrigan and colleagues (2013) conducted a retrospective analysis on hospital readmission for CRBSI and the effectiveness of ethanol lock therapy (ETL) and 93 subjects on home PN and/or home IV fluids had 106 hospital readmissions. The researchers reported there was a trend toward significance in the relationship with hospital readmission and ETL use with a p value of .056 (Corrigan, et al., 2012).

There were no significant predictors from the context dimension for acute care readmission in this sample. Additional research is indicated to examine if there are other factors beyond complications that are predictive of readmission.

Research Question 4: What is the relationship between the process dimension factor, type of educational model utilized, and the proximal outcome variable, individual and family engagement in care?

The educational model was expanded in 2013 from solely individual patient and/or caregiver lessons to include group lessons with multiple families and caregivers. However, for this sample, only 3 or 2.5% of people received group lessons – all others

(117/ 97.5%) still received individual lessons at the bedside. The aim was to examine if the type of lesson received, had an impact on the level of individual and family engagement in care. Examination of the relationship between PN education and individual and family engagement in care was not found in the literature. Further exploration would help determine reasons for the predominance of individual lessons in this sample. The fact that this was a first-time experience with home PN for these subjects could have indicated the need for one-on-one instruction based on the nurse's evaluation to assure optimal preparation prior to discharge could have been a factor or perhaps scheduling with multiple patients/families for lessons was prohibitive.

There has been limited scientific study on education methods for teaching patients home management of PN. Messing and Jolly (2006) report the educational model in place at their institution in France at the time of writing, included fifteen sessions – five per week for three weeks provided by a dedicated hospital nurse. Three criteria were identified as essential for educating patients were, first, a patient that comprehends the need for PN; secondly the patient should have and be able to cope with a stable somatic condition and lastly the patient should have emotional control (Messing & Jolly, 2006). The European Society on Parenteral and Enteral Nutrition or ESPEN (2009) along with Gifford, DeLegge and Epperson (2010) emphasize the importance of providing education to patients prior to going home with PN and ESPEN (2009) stresses that only skilled practitioners should complete this training with patients. Gifford and colleagues (2010), discuss teaching strategies and believe that the while teaching begins in the acute care setting, it is important that it continue in the

home with the dietician and home infusion nurse providing supportive instruction in the home setting.

The current practice in this medical center as previously discussed, is to provide lessons with patients and family members prior to discharge with home care and infusion nurses continuing with training in the home which is consistent with the recommendations. The number of lessons given to each patient/caregiver averages out to one or two lessons prior to discharge from the acute care medical center, however lessons continue in the home with home care and home infusion nurses. Nurses visit the home twice daily initially to teach infusion initiation and discontinuation procedures along with other important daily tasks.

There is a great need for additional research on educational methods for teaching home PN. Gruman and colleagues (2010) discuss the importance of the role that patient education professionals can play in facilitating greater levels of patient engagement in healthcare, through the use of targeted public education campaigns and broader use of innovative strategies. But individual and family engagement in care might also be enhanced through the implementation of some of these same strategies.

It is particularly important to explore the effectiveness of teaching strategies and to evaluate if there are trends related to health outcomes in individual and group lessons and use of supplemental instructional materials such as videos, or online programs that may impact health outcomes

Research Question 5: What is the relationship between the proximal outcome variable individual and family engagement in care, and the distal outcome variable acute care readmission?

The level of individual and family engagement in care was not a significant factor in predicting readmission even though it is reported in the literature that higher levels of activation, viewed by some as a component of engagement, are associated with better outcomes and lower health related costs with other patient populations (Hibbard, et al., 2004). The noted variability in how engagement is defined, measured and interpreted may be a contributing factor to this mismatch. This study sought to examine individual and family engagement in care which is inclusive of interaction, communication, collaboration and coordination with the health care team. Engagement at this foundational level is more immediately applicable and critically important the safety and well-being of individuals and families involved in PN care.

Other researchers view engagement on a continuum that may transcend to community involvement and policy development (Carman, et al., 2013). Further investigation is merited for delineation of models for patient engagement particularly for use with patients and families self-managing chronic complex conditions.

Summary

This exploratory examination of the IFSMT model with the home PN population provided responses to some questions and raised additional questions to be investigated. The challenges do not complexities do not outweigh the benefits for better health outcomes for the individuals using this therapy.

Chapter 5

Summary

The purpose of this exploratory, descriptive retrospective analysis of an existing data set was to examine the Individual and Family Self-Management Theory (IFSMT) and the relationships among the context and process factors and proximal and distal outcomes among adults on home parenteral nutrition (PN) and their families.

Relationships among the context variables: gender, age, race/ethnicity, geographic location, residence in a health provider shortage area, insurance provider, PN rationales, PN duration, family and caregiver support; and process variable: educational model; and proximal outcome variable: individual and family engagement in care, and the distal outcome variable, acute care readmission, were described.

Data for this study were extracted from the IRB-approved home parenteral nutrition database, the electronic health record and the records of the educational instruction provided. The final sample of 120 subjects were new to home parenteral nutrition in 2013 and had been active with PN therapy for a minimum of 30 days and their care was managed by the nutrition support teams of the 1000-bed Midwestern medical center. The sample consisted of 53 males and 67 females whose ages ranged from 20 to 84 years. The sample was racially/ethnically diverse and included white, black, Hispanic, Asian, Arab and multiracial, however, whites were the predominant race with an n/% of 100 (83.2%). Subjects came from 17 different states/territories and internationally from Saudi Arabia. The largest number of subjects came from Ohio as 84 or 70%.

All three community types are represented in the sample and consisted of subjects from urban, urban cluster and rural locations, but for data analysis purposes, they were examined as non-rural and rural. Twenty-five subjects (20.83%) came from Health Provider Shortage Areas and 95 (79.17%) did not and severity of need scores for the HPSAs ranged from 4 to 19 with higher numbers representing a greater need. Insurance provider types included commercial, Medicare, Medicaid and dual eligible and uninsured and self-pay or private pay. The largest group of subjects – 78 (65%) had commercial insurance or were private pay which meant payment was submitted from non-insurance provider funds/ private funds. Medicare, Medicare, dual eligible and uninsured subjects numbered 42 or 35% of the total sample.

Reasons for requiring home PN were categorized into the created variables according to n/%: short bowel syndrome or malabsorption, 45 (37.5%); obstruction or ileus 31 (25.8%); fistula or perforation 23 (19.3%) and other 21 (17.5%). The length of PN therapy in number of days ranged from 30 to 362 with a mean of 100.6 days, SD \pm 72.4 days and median of 73.5 days.

Twenty-one subjects chose to be their own primary care provider in management of PN therapy and 68 (56.7%) unpaid family members or a friend singly managed care, most commonly a spouse 37 (30.8%) while 31 unpaid family caregivers shared management responsibilities with another individual and subjects paired with spouses were largest in number at 10 or (8.3%).

Post-acute health care provider contact, defined as physician visit, ER visit or observation stay, exclusive of home care visits or outpatient clinic visits with NST,

occurred for 92.5% or 111 of the subjects. Only 9 subjects or 7.5% did not have health post-acute health provider contact.

The most common primary diagnoses of subjects in this sample were cancer n=29 (24.2%) Crohn's disease n=27 (22.5%); and ulcerative colitis n=6 (5%). Twelve different types of cancer were noted from those with that diagnosis with the greatest frequency being colon cancer, 7 (5.8%). There were 50 subjects (41.67%) with ostomies and 70 subjects without them or 58.33%. Twenty-one or 17.5% of subjects had 1 or more fistula and 99 or 82.5% had no fistula.

Pertinent Findings

Individual and family engagement in care was explored with the PN population in this study and although findings cannot be generalized to other populations, the results did reveal that this is an important concept that merits further investigation with persons receiving PN and other complex populations especially as more care transitions to the home setting. It is unclear why there was not a significant relationship between individual and family engagement and readmission.

Subjects who were female, as well as those from urban areas were more likely to be fully engaged. In addition, subjects with PN rationale, short bowel syndrome or malabsorption were more likely to be fully engaged as compared to those with obstruction or ileus. For every day of PN therapy, the likelihood of not being fully engaged decreased by almost 1% which is a positive outcome as one would hope that continued therapy would enhance engagement.

The evidence supports that complications experienced with persons on home PN patients are associated with increased risk for acute care readmission. Comorbidities

and disease complexities do account for readmissions, which was supported by the significance of short bowel syndrome and malabsorption in this study, which was the only significant variable for acute care readmission. Thus, subjects with short bowel syndrome and malabsorption were noted to be more fully engaged as compared to those with obstruction or ileus and had more acute care readmissions as compared to those with fistulas and perforations. Of those with SBS/malabsorption 45 or 37.5% of the sample, subjects with Crohn's disease numbered 27 or 60%.

Post-acute health provider contact in this population requires additional exploration based on the finding that 92.5% of the sample or 111 individuals had physician or ER visits or observation stays while on PN therapy in addition to being active with home care and/or infusion agencies indicating high utilization of health care resources.

Knowledge and skill acquisition is important for provision of safe, high quality care and even though it was not fully examined in this study, current recommendations in the literature for additional scientific study of educational models is necessary to determine what models may be most beneficial in supporting individuals managing PN therapy.

Limitations

The existing dataset provides a wealth of opportunity for investigation of previously explored problems from a different perspective. Knowing the purpose for which any given dataset was created helps guide the inquiry for answers. The Home TPN database was created for more effective clinical management of PN patients while inpatient and at home with the focus on clinical parameters, formulation specifications

and tracking of patient results necessary for prescribing PN which support the safe delivery of care, however, it limits the scope of what can be gained to advance knowledge.

The limitations of secondary data analyses are that the examination of variables is limited to what has been collected and as a consequence there is no input into the sample selected, type and quality of data collected, or the method of data collection (Grady & Hearst, 2007). This was a non-random sample and data were extracted from the database for the year 2013 and it is representative of what occurred during that timeframe only. Some of the data extracted were based on patient submission of self-reports such as intake and output records and daily weights –most were later verified by staff, but the researcher would not have control over these procedures and would have been unable to confirm the accuracy of what was reported.

Other limitations identified by Schlomer & Copp (2013) are that longitudinal follow-up may be limited or not possible at all. Data cleaning and management remain important concerns with secondary analysis particularly if there are inadvertent errors in data entry or if missing data are incompletely described or included in unexplained categories (Magee et al., 2006).

The results of this study cannot be generalized to other populations due to the exploratory, descriptive design of this study. Replication and additional examination with a larger sample for more comprehensive analysis is recommended because some variables of the study could not be fully explored due to the small group sizes such as race/ethnicity, the rural population and residence in a Health Provider Shortage Area.

Implications for Knowledge Development

The Individual and family self-management model was the guiding framework for this study. The overall model of four predictors: gender, geographic location, SBS/malabsorption as compared to obstruction/ileus, and PN duration was able to statistically distinguish between being fully engaged and not fully engaged and correctly predicted 70% of the cases, however, only 32% of the variance was explained by the model for the proximal outcome variable, individual and family engagement in care.

There was less statistical support for use of the model in examining acute care readmission. The model correctly predicted 68.3% of the cases and SBS/malabsorption as compared to fistula/perforation was significant, but only 15 % of the variance was explained by the model for the distal outcome variable, acute care readmission.

Further validation of the engagement measure is necessary as this was an evidence-based exploratory examination with a population of individuals with multiple complexities. Expert clinicians were surveyed and identified behaviors felt to be reflective of engagement with this population. There were no examples of engagement in the literature that have been explored with individuals on PN. Measurement validity and reliability needs to be established with larger samples and among other populations.

Qualitative and prospective research is needed to learn more about readmission, education and engagement in care. The American Society for Parenteral and Enteral Nutrition's, Sustain Registry established in 2012, now offers an opportunity to conduct scientific exploration with larger sample sizes through the use of de-identified aggregate data. Public use and scientific inquiry, data analysis and dissemination of results is encouraged. Broadening data collection for the Home TPN database to include

additional outcome-based data such as functional status, quality of life, engagement in care activities and beyond acute care readmission, and complications provides an enhanced opportunity to grow the science.

Implications for Practice

Subjects resided in all three community types from 17 states/territories and from international locations. Managing the complexity of arrangements and coordinating care among multiple physician providers, agencies sometimes locally in addition to the patient's home area requires great skill, professionalism and often negotiation.

Subjects in this sample had a 62% readmission rate. A pilot program connecting community-based and specialty care coordinators, and Primary care physicians with inpatient health care providers as a part of the continuum of care, is being implemented at the medical center which may assist in addressing this issue. The aim of this initiative is to foster communication during transition of care as well to support individuals and families involved in PN care with the ultimate goal of decreasing readmissions. In addition, having increased awareness of the high readmission rate among individuals on PN therapy, provides an opportunity for the physicians and the NST to be more vigilant in symptom management and instruct the patient on what symptoms to report.

Complex care in the home provides is an opportunity for implementation of a cadre quality measures for safe and effective care. Home care agencies, individuals and families could be instrumental in continuing to refine what encompasses safe care.

Implications for Policy

Through the Affordable Care Act and other legislative measures have the potential to more reimbursement or coverage for necessary services for patients and caregivers managing an expensive therapy, but many of the initiatives are evolving so the exact benefit to beneficiaries is still unknown. The Medicare Infusion Act was proposed in January, 2015 to help address the costs associated with infusion therapies such as home PN (U.S 114th Congress, 2015). HPSAs require additional funding to help lighten the financial burden for supply and equipment needs particularly for those on long term PN therapy with more access challenges. Funding for Nutrition research is noted to be a priority with the current U.S. government administration with fiscal initiatives in support of additional research to advance nutritional science and improve access to care (U.S. Department of Health and Human Services, 2015).

Recommendations for Future Research

Recommendations for future investigations have been offered throughout this document, but to summarize, the topics listed below could provide the basis for knowledge development with this complex population:

- Racial disparities, access and urban and rural differences
- Engagement behaviors and individual and family self- management
- Interdisciplinary care coordination and assisting individuals and families in care transition across the continuum.
- Prospective evaluation of barriers and facilitators to safe, high quality care
- Examination of burden of care with shared caregiving in a complex care environment

Summary

This study explored Ryan and Sawin's (2013) Individual and family self-management theory in the home parenteral nutrition population. The model proved to be useful in identifying factors related to individual and family engagement in care and acute care readmission that with continued investigation can add to the science of complex individual and family self-management and parenteral nutrition care.

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