THE ROLE OF RELATIONSHIPS DURING
CHRONIC CRITICAL ILLNESS

by

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Submitted in partial fulfillment of the requirements

For the degree of Doctor of Philosophy

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CASE WESTERN RESERVE UNIVERSITY

August, 2011
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Dedication

I dedicate this work, in part, to my study participants. Their generosity, granting me the privilege of access to their relationships, tribulations and victories, allows me to give new voice to the most important perspective of the chronic critical illness experience: the patient’s. I pray that I have honored their trust.

To my husband, Greg, I also dedicate this work. From the first step of the journey, through countless highs and lows, you have been constant love, support, motivation, indulgence and humor. We arrive together at this moment, and I am truly blessed to call you mine.
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In an undertaking of this magnitude, there are times when one feels utterly alone: late nights studying, afternoons reading, weekends at the computer. And, while it is true that the work is ultimately my own, the greater truth is that it could never have been completed without the enduring support and input of countless others. On these pages, I acknowledge several from the countless who have, time and time again, made what seemed to be a solo journey into a rich collaboration, the product of which is contained in the chapters that follow.

Dr. Patricia Higgins: Thank you for your invaluable insight and introductions into the amazing world of the researcher, writer and educator. Your integrity and body of research will forever light my path. I shall always seek the high road, because our patients deserve nothing less.

Dr. Carol Musil: You were my first professor at FPB, and helped me realize that when ideas are shared among colleagues with a commitment to the greater good, wonderful things can happen. Thank you for seeing me safely home.

Dr. Mary Quinn Griffin: Thank you for opening the world of technology and innovative teaching to me. I will always remember your kind spirit and enthusiasm for collaboration.

Dr. Christopher Burant: Thank you for your expertise in statistical methods and patience in helping me to arrive at logical conclusions on my own. Thank you for believing in me.

Dr. Rana Hejal: Thank you for your commitment to the critically ill patients who are in your care. Your passion and expertise make a powerful combination that is inspiring to patients, families and colleagues alike.

To Adam, Cori, Mom and Dad, and Mom Lee: Whether or not you knew, you were in my every thought and move throughout these long years of pursuing the doctorate. As cheerleaders, suppliers of love and affirmation and, most importantly, reminders of what is really important after all, I couldn’t ask for better than each of you.

To Kathy Cunningham: You set an example for me of what a nurse researcher can be to nursing: knowledgeable, committed to excellence, and completely patient-focused. What is more, you are my true friend, in every sense of the word ‘true’.
To Dr. Bruce Schmidt: You have been a mentor who always knows when to push, when to pause, and when to simply listen. Your passion for a rigorous study that takes patient care and professional practice to higher levels is what motivates; whether you are in the office down the hall, or on the other side of the country (practically). That - and your guitar-playing.

The Frances Payne Bolton School of Nursing Alumni Association for partial support of this research study.

Lastly, to the Grand Author: I began my journey to become a researcher by seeking You. In You, I came to understand that chronically critically ill patients are in need of healing beyond traditional therapies, and shaped this study so their need for relationships could be heard. Let this work be a step toward meeting that need. Let it be a reflection of Your light in our world.
This study investigated associations among relationships, states of relatedness, comfort, and therapeutic physical activity in chronically critically ill (CCI) patients. The study framework, developed from Hagerty and colleagues’ Theory of Human Relatedness and Kolcaba’s Comfort Theory, emphasizes the centrality of relationships, states of relatedness, comfort as an holistic experience, and the health-seeking behavior of therapeutic physical activity.

This study used a convenience sample of 24 CCI adults admitted to a long-term acute care hospital. Participants completed the Visual Measure of Relatedness (VMR), the Chronic Critical Illness Comfort Questionnaire (CCICQ), and the Functional Independence Measure™ (FIM) at two time points: upon enrollment and one month later. Six participants were randomly chosen to participate in a second part of the study, yielding Social Network Analysis (SNA) data using the Social Network Questionnaire and additional VMRs. Descriptive and correlational statistics were used to investigate associations among relationships, states of relatedness, comfort, and therapeutic physical activity. Relationships are described using graphical analysis and Pajek®-generated sociograms.

Results indicated most participants perceived a state of connectedness with important relationships despite lengthy illness periods, however there was a
tendency towards disconnectedness over time. There was a statistically significant association between states of relatedness and holistic comfort at baseline and over time, but not between states of relatedness and therapeutic physical activity. Egocentric sociograms created from SNA data for relationships that participants identified as ‘important’ suggest that family and friends constitute the major portion of a CCI patient’s social network.

This study will advance nursing science and practice through new insights into relationships, comfort and physical functioning in the CCI. The instruments and methodology of the VMR and SNA are relatively new to clinical studies.
Chapter I

Background and Significance

“The person is interdependent and lives in reciprocity, connection, affiliation, and relationship. Through dialogue and exchange, together with self-reflection, the person makes meaning”

(USA Nursing Knowledge Consensus Conference, 1999, p.1).

Human beings are driven to establish and maintain close relationships in order to satisfy many basic needs; a primary example of these needs is comfort (Baumeister & Leary, 1995; Hazan & Shaver, 1994). Beyond basic needs, individuals grow and thrive through their affiliations and bonds with others (Hagerty, Lynch-Sauer, Patusky & Bouwsema, 1993), particularly those characterized as contributing to a sense of well-being. There is growing scientific evidence supporting the connection between relationships and health and well-being (Choenarom, Williams & Hagerty, 2005; Cacioppo, et. al., 2002).

As a result of prolonged hospitalization and complicated medical care, chronically critically ill (CCI) patients must forge new relationships while simultaneously coping with the disruption of established relationships, thus compromising their comfort and, potentially, their physical healing. Although the promotion of patient comfort is germane to nursing (Kolcaba, 1992), care in the intensive care unit (ICU) is predominantly directed at preserving the patient’s physiologic functions; consequently, it is not surprising that support and development of relationships may not receive high priority. However, using
relationships as a means to promote comfort may have implications for CCI patients’ health and well-being that, as yet, have not been investigated by researchers.

Another means for promoting the health and well-being in the CCI is through patient engagement in therapeutic physical activities, such as physical therapy, occupational therapy, and early mobilization. Current evidence regarding the discharge disposition of CCI patients suggests a need to improve their physical function. Nearly 80% of the CCI patients followed by Daly, Douglas, Kelley, O’Toole and Montenegro (2005) were discharged to a long-term care facility following their index hospitalization, many because of an ongoing need for physical assistance and rehabilitation. These data are consistent with other ICU patient populations who had prolonged hospital stays (Claridge, Croce, Weinberg, Forsythe, Miller & Fabian, 2006).

Within Kolcaba’s Comfort Theory, (2001), a basic assumption is that when patients are comforted they are strengthened in ways that enhance the likelihood they will engage in health-seeking behaviors that promote healing. For CCI patients, engaging in therapeutic physical activity is an important health-seeking behavior and nurses commonly use a number of comfort measures, such as medication or positioning, to assist them in their efforts. But by expanding their repertoire of interventions to include facilitating relationships, nurses may promote comfort and optimize patient engagement in the important health-seeking behavior of improving physical abilities, with the goal of resuming an
independent life in the foreseeable future. There is no published literature that
describes the linkages among relationships, comfort and physical activity during
chronic critical illness; thus, it is an important and innovative opportunity for
research.

**Purpose of the study**

The purpose of this study is to investigate CCI patients’ perceptions of their relationships during their illness and investigate associations among their relationships and states of relatedness, comfort, and therapeutic physical activity, during hospitalization and one month following hospital discharge. By enhancing our knowledge of the role relationships play during chronic critical illness, nurses may better promote patient comfort and enhance the patient’s likelihood of engaging in health-seeking behaviors that contribute to their recovery.

**Background & Significance**

More than five million patients are admitted to Intensive Care Units in the United States each year (Society of Critical Care Medicine [SCCM], 2006). The severity and duration of a critical illness is influenced by various factors, such as co-morbidities, advanced age, unexpected adverse events, or difficulty weaning from mechanical ventilation. Owing to the wealth of medical advances during the past century, survival of a critical illness is more likely than ever; consequently, this has created a sub-population of the critically ill, the “chronically critically ill”, whose need for ICU services and life-support is
prolonged (Daly, Rudy, Thompson, & Happ, 1991; Martin, Hill, Burns, & Chen, 2005). In the United States, the average ICU length of stay for a critically ill patient is between 6.1 and 9.3 days (SCCM, 2006). However, a CCI patient requires ICU services and care beyond a 10 day period (Halpern, Pastores & Greenstein, 2004), and the illness period frequently extends beyond the index hospitalization, with the patient requiring prolonged care in a rehabilitation hospital or other post-acute facility. Length of stay is just one of the challenges faced by patients, family members, and staff in terms of achieving and maintaining satisfying relationships in this setting. Prolonged mechanical ventilation, use of sedating agents, and restricted visiting hours can also be obstacles to patient-other relationships (Stein-Parbury & McKinley, 2000).

Although the patient’s perspective regarding relationships during their illness is relatively unknown, there has been substantial research on what family members value when a loved one is critically ill (Daley, 1984; Berwick & Kotagal, 2004; Lederer, Goode & Dowling, 2005; Browning & Warren, 2006). Molter’s (1979) and Leske’s (1986) work with the families of critically ill patients underscored the priority people place upon relationships during crisis. According to the Critical Care Family Needs Inventory (CCFNI) (Leske, 1986; Leske, 1991), five of the ten most important needs identified by families were to feel hospital personnel cared about the patient, have a waiting room near the patient, be called at home about changes in the patient’s condition, receive information about the patient once a day, and be allowed to see the patient
frequently. A common thread among families’ needs during critical illness is the
nurse’s support of their relationship with the patient. This need is a transcultural
phenomenon, as indicated by the use of the CCFNI by researchers in Belgium,
China, and France (Bijttebier, et al., 2000; Leung, Chien & Mackenzie, 2000;
Azoulay, Pochard & Chevret, Lemaire, Mokhtari, Le Gall, et al., 2001). These
studies confirmed Molter’s original findings regarding the importance assigned
to interpersonal communication and family contact with the patient. Research is
now necessary to describe the CCI patient’s perception of relationships and
investigate linkages between patient relationships, comfort and physical
functioning.

**Conceptual Framework**

The conceptual framework for the study was developed from the Theory
of Human Relatedness (Hagerty, Lynch-Sauer, Patusky, and Bouwsema, 1993)
and Kolcaba’s Comfort Theory (1994). The purpose of a conceptual framework is
to provide a frame of reference for conceptual relationships within which the
researcher can generate and analyze data, and derive conclusions about relevant
phenomenon. The framework provides a structure that drives the generation of
knowledge in a logical and coherent manner. Key concepts drawn from the
Theory of Human Relatedness (Hagerty, Lynch-Sauer, Patusky, and Bouwsema)
and Kolcaba’s Comfort Theory (1994) are relationships, particularly with regard
to the influence of different states of relatedness, comfort as an holistic
experience, and the health-seeking behavior of therapeutic physical activity.
The Theory of Human Relatedness contributes to this research with its illustration of states of relatedness that contribute to a sense of well-being. It is logical to expect that a person whose relationships contribute to a sense of well-being is better poised to experience a state of overall comfort. Likewise, a relationship that detracts from a sense of well-being may also impede the overall experience of comfort. Kolcaba’s Comfort Theory is relevant to the study of relationships during chronic critical illness as it underscores the importance that comfort has in promoting recovery via health-seeking behaviors. Together, these frameworks illustrate and explain the importance and dynamics of human relationships, particularly as they relate to the desired nursing outcomes of comfort and health-seeking behaviors.

**The Theory of Human Relatedness**

Hagerty, Lynch-Sauer, Patusky, and Bouwsema, in their description of their Theory of Human Relatedness (1993), propose that human beings exist in relation and that relatedness is an inborn functional, behavioral system rooted in attachment patterns. Further, the authors posit that a lack of connection may predispose a person to major illness – psychological, physiological, and/or spiritual. They define relatedness as “an individual’s level of involvement with persons, objects, groups or natural environments and the concurrent level of comfort associated with that involvement” (Hagerty, et al, 1993, p.292). Like Kolcaba, the authors suggest that comfort, in the context of relationships, influences one’s sense of well-being. Healthy relatedness is posited to depend
upon dynamic movement between states of connectedness, disconnectedness, parallelism, and enmeshment (Hagerty, et al., 1993).

Figure 1 illustrates the central concepts of the Theory of Human Relatedness (THR) and its link to comfort. According to the THR, there are four states of relatedness: connected, disconnected, enmeshment, and parallelism. These four levels are based upon the degree of involvement and level of comfort associated with it; for example, to be connected is to perceive a high level of involvement and a corresponding high level of comfort, while disconnected is to perceive a low level of involvement and a low level of comfort. Within the Theory of Human Relatedness, it is important to understand that the four states of relatedness are not on a continuum, but rather reflect the dynamic process of being in relation with others and self throughout the experience of life.

**Figure 1. States of Relatedness¹; x-axis = level of comfort, y-axis = degree of involvement.**

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This theoretical framework has been used to describe the nurse-patient relationship (Hagerty & Patusky, 2003), investigate the role of sense of belonging, social support, and loneliness in depression (Hagerty & Williams, 1999), and guide treatment of fatigued women (Patusky, 2002). As a result of these studies, the authors provided data to support further research in psychological and physiological benefits from positive states of relatedness (Hagerty & Patusky, 2003).

Comfort Theory

Kolcaba’s Comfort Theory conceptualized holistic comfort as a desired outcome of nursing care. One of the basic assumptions of this middle-range nursing theory is that human beings are innately driven to seek comfort, either actively or passively (Kolcaba, 1994). The definition of comfort is the immediate state of being strengthened that results when our needs for relief, ease, and transcendence are met (Kolcaba, 1992). The state of being strengthened, according to Kolcaba’s theory, predisposes an individual to engage in health-seeking behaviors, which can be internal and external. The opposite of comfort, according to Kolcaba, is suffering, which is more than the presence of pain (2003). The Theory of Comfort is an holistic perspective that takes into account physical, psychospiritual, sociocultural, and environmental aspects (Kolcaba, 2003) of the world in which we live.
Figure 2. Central concepts of The Theory of Comfort\textsuperscript{2}


Figure 2 illustrates the central concepts of The Theory of Comfort.

Comfort, as depicted in this framework, is experienced as relief, ease, or transcendence. Relief is broadly described as the experience of having a specific comfort need satisfied. Ease is described as a state of contentment or calm. Transcendence is that state in which an individual is able to rise above their problems or pain (2003). These comfort experiences, identified as ‘states’ by Kolcaba, are interconnected and often overlapping.

There are four contexts in which comfort may be experienced: physical, psychospiritual, sociocultural, and environmental. The physical context of comfort refers to bodily sensations or functions; the psychospiritual context addresses that which gives one a sense of meaning in life; the sociocultural context refers to interpersonal and inter-societal dynamics; the environmental context of comfort pertains to all that is external to our person. As with comfort states, the contexts in which one experiences comfort often overlap and influence one another.
The three states of comfort can be realized within any or all of the four contexts, but it is not necessary for one to experience comfort in all contexts simultaneously in order to be predisposed to health-seeking behaviors. Health-seeking behaviors, a nursing outcome first identified by Schlotfeldt in the 1970’s (Kolcaba, 2001), are an important consequence of comfort in that they represent enhanced patient health and well-being, the ultimate desired nursing outcome. Relevant to this study, comforting relationships with people and/or technology may promote a CCI patient’s health-seeking behavior of physical activity.

Conceptual Framework/Study Model

Figure 3. Study Model

Figure 3 represents the study model. Within this conceptual framework, there is a subtle, but important, distinction between involvement-derived comfort and comfort. The former is dependent upon a person’s involvement and comfort as they pertain to relationships; the latter is a person’s overall perception of comfort experienced during chronic critical illness. This distinction was
Acknowledged by the use of separate measures and description during the course of the study.

According to Baumeister & Leary (1995), human beings have an innate need to be in relationship with one another; it is nearly as essential as food and shelter. Because relationships, and the comfort they can engender, are an innate human need, it is important to better understand their role in a chronically critically patient’s health and well-being. With this knowledge, nurses may better promote factors that contribute to a CCI patient’s optimal recovery. The study model describes the role relationships play in promoting patient comfort and influencing health-seeking behaviors, such as therapeutic physical activity.

Theoretical definitions of terms

A relationship is an individual’s perceived attachment to another person, object, or idea that will meet the individual’s perceived needs for comfort (Hazan & Shaver, 1994). Comfort is the immediate state of being strengthened that occurs when one’s need for relief, ease, and/or transcendence is met (Kolcaba, 1992). Finally, health-seeking behavior is defined in this study as an individual’s behavior or action that contributes to well-being (Kolcaba, 1992).

Operational definitions of terms

Based upon the theoretical definitions, the following definitions have been identified to operationalize key concepts in this study. A relationship is a perceived bond or sense of connection between the CCI patient and another person or object. The concept of relationships was operationalized by two sub-
concepts: relatedness states and network features. Relatedness states was derived from a CCI patient’s description of his or her relationships with regard to level of involvement and accompanying sense of comfort (involvement comfort) (Hagerty, et. al., 1993). This was measured using the two-item investigator-developed visual analogue scale, the Visual Measure of Relatedness. Network features, identification of contacts and frequency of interactions, was operationalized by Social Network Analysis (SNA). SNA is an emerging tool in nursing research that provides a quantitative description of relationship structure and function.

Comfort level is patient-expressed and was measured using the Chronic Critical Illness Comfort Questionnaire, which was adapted from Kolcaba’s Hospice/End-of-Life Questionnaire. The adapted tool includes an item identified from the literature (Hupcey, 2006) as relevant to the critical care setting.

Health-seeking behaviors, identified as physical function, were operationalized as level of therapeutic physical activity using the Functional Independence Measure (FIM) (State University of New York at Buffalo, 1990). This tool is regularly employed in the rehabilitation setting to plan and evaluate progress in multiple forms of therapy (physical, occupational) (Houlden, Edwards, McNeil & Greenwood, 2006) and has been used on a limited basis in patients recovering from episodes requiring prolonged mechanical ventilation (Chiang, Wang, Wu, Wu & Wu, 2006).
For the purposes of this study, a CCI patient is an adult patient aged 21 years or older who required life-sustaining therapies in an ICU setting ≥ 7 days and was subsequently admitted to a long-term acute care hospital.

**Research Questions**

This study will answer the following questions for chronically critically ill (CCI) patients who require admission to a Long-term Acute Care Hospital (LTACH):

1. How do CCI patients describe relationships with family and friends, health professionals, and objects, in terms of states of relatedness and network features, on admission to the LTACH and one month after admission?

2. What is the CCI patient’s level of comfort, on admission to the LTACH and one month after admission?

3. What is the CCI patients’ level of therapeutic physical activity, on admission to the LTACH and one month after admission?

4. What is the association between the CCI patients’ level of comfort and performance of therapeutic physical activity on admission to the LTACH and one month after admission?

5. What are the differences among the CCI patients’ states of relatedness in terms of perceived level of comfort, and performance of therapeutic physical activity?
Assumptions

1. Humans thrive and grow in the context of complex and dynamic relationships.

2. Within the context of relationships, human beings have the potential to realize value and meaning in life and its experiences.

3. Critical illness alters the patient’s ability to achieve and/or sustain satisfying states of relatedness.

4. Critical illness is a time when a patient may experience alteration and/or deprivation of satisfying relationships.

Summary

The biopsychosocial importance of relationships to human beings has been established in the literature. A primary motivation for close attachments is comfort (Hazan & Shaver, 1994; Bowlby, 1954). In life’s times of uncertainty the comfort of positive states of relatedness may lead to important psychological and physical benefits, such as greater overall comfort and physical function (Baumeister & Leary, 1995). It is possible that a prolonged critical illness is one of life’s most uncertain times. There is a shortage of empiric knowledge about the link between relationships and the CCI patient’s experiences and outcomes. Within the study model this study sought to contribute to the knowledge of and evidence regarding the role of relationships in the CCI patient’s experience.
Chapter II
Review of the Literature

Introduction

The review of the literature serves to inform the reader of the theoretical underpinnings, current background, and empirical evidence related to the study of the role of relationships in the chronically critically ill (CCI). This literature review begins with a description of the conceptual model that will guide the study of relationships and comfort in the CCI, derived from the frameworks of the Theory of Human Relatedness (THR) (Hagerty, et al., 1993) and the Comfort Theory (Kolcaba, 1994). This model provides the patients’ perspective on the role of relationships during chronic critical illness by recognizing the influence of relatedness in the human experience of comfort and engagement in health-seeking behaviors.

Following the description of the study model, literature relevant to the concepts of relationships, comfort, and health-seeking behaviors, particularly physical activity, will be presented. The next portion of the literature review will be devoted to studies that address associations among relationships and comfort, relationships and health-seeking behaviors, and comfort and health-seeking behaviors. The review will conclude with a summarization of literature presented and its relevance to the research study.
It is important to note that much of the literature available regarding these concepts and relationships is descriptive and qualitative. The body of knowledge regarding the role of relationships during chronic critical illness, particularly as to their influence on patient comfort and engagement in health-seeking behaviors is limited. However, the evidence that does exist, as presented in this paper, underscores to the importance of the concepts and the study.

**Relationships, Comfort and Physical Function in the Chronically Critically Ill**

The model for the study of relationships and comfort in the CCI population was developed from the author’s inquiry into the concepts of relationships, comfort, and health-seeking behaviors, to study their associations during chronic critical illness. The author’s model suggests that, during chronic critical illness, relationships exert an influence upon both patient comfort (direct) and health-seeking behaviors (direct and indirect), that may be instrumental in the healing process. In addition, the study model posits a direct association between comfort and the health-seeking behavior, therapeutic physical activity. When a patient experiences comfort they are more likely to engage in physical activity that may promote recovery. This study explored these concepts and their associations.

Morse (2000) states that trust within a caring relationship is essential to the achievement of optimal comfort. Similarly, Hazan and Shaver (1994) posit that secure and consistent relationships are essential to the experience of comfort. They assert that when relationships become inconsistent, whether for physical or
psychological reasons, anxiety frequently results. Within the intensive care unit (ICU) environment, by virtue of the urgency of the situation as well as a possible myriad of obstructing factors (mechanical ventilation, altered levels of consciousness, imposed visiting hour restrictions) it is not surprising that the patient’s usual relationships may transition from some degree of physical and psychological consistency to inconsistency, and consequently, detract from individual comfort. In times of chronic critical illness, when so many factors impact patient comfort, the influence of relationships and states of relatedness may be best viewed as an opportunity to facilitate comfort.

Relationships also exert a direct influence upon the likelihood an individual will engage in health-seeking behaviors, according to the study model. Patusky’s work with fatigued women (2002) found that certain states of relatedness, namely disconnectedness and parallelism, may be influenced by an individual’s energy levels and motivation to be involved. Interestingly, results from her investigation suggested that disconnectedness contributed to feelings of isolation, but parallelism served as a cushion that allowed subjects to focus on their health and participating in activities which contributed to overall improvement. Thus, while relationships themselves are the medium in which humans grow and thrive (Hagerty, et al., 1993), the optimal state of a relationship may not always be characterized by a high degree of involvement. It is possible, for example, in the CCI population, where fatigue is a common experience (Higgins, 1998), that relatedness states characterized by low levels of
involvement may protect energy stores, thus facilitating greater participation in therapeutic physical activities, such as range of motion exercises or physical therapy. The influence of relationships in general and the various states of relatedness, specifically, on a CCI patient’s health-seeking behavior of physical activity requires clarification in order for nurses to intervene appropriately.

Comfort has long been recognized as a primary objective of professional nursing (Kolcaba, 1992). Perhaps this is due, in part, to the awareness that human beings are, by nature, in constant pursuit of comfort, consciously and subconsciously (Kolcaba, 2001). Kolcaba asserts that when comfort needs are met, patients are strengthened and motivated to meet treatment goals. This is consistent with the Latin origin of the word *confortare*, which means "to strengthen greatly" (Morse, 2000). Along a continuum, comfort can be described as: relief (low end, just having a comfort need met), ease (middle range, contentment and well-being), and transcendence (high end, whereby a comfort need was met to such an extent as to produce an energized or inspired state with the potential for optimal performance) (Kolcaba, 1992). According to Morse (2000), when nurses facilitate comfort, the short-term goal of relief of suffering may be realized. Equally important, when comfort is experienced, the patient is better-positioned to achieve long-term health goals, even when smaller distresses must be endured, such as those which accompany ambulation following surgery. The CCI patient’s task performance with regard to physical activity is an important factor in achieving many long- and short-term health goals. Thus the
relationship between comfort and this health-seeking behavior warrants investigation.

The study model posits associations between relationships, comfort, and health-seeking behaviors. Knowledge of the role of relationships and comfort on health-seeking behaviors during chronic critical illness has significance for a) the theoretical basis of nursing care, b) the clinical behaviors of critical care nurses, c) the educational preparation of critical care nurses for patient-focused care, d) the ongoing conceptualization of relatedness and its subordinate terms, and e) the influence of the support of relationships on the care pathway for CCI patients. As Nightingale’s words remind us that nurse’s observations and actions serve to save patients’ lives as well as increase their health and comfort (Notes on Nursing, 1859/1992), the study was designed with those words in mind.

**Relationships**

The social sciences have a long tradition of the study of human relationships. In the late 1950’s, Harlow observed that the mission of psychologists, to completely understand all facets of human behavior, was far from accomplished (Hazan & Shaver, 1994). At that time, the majority of evidence regarding human attachments and affections was the result of observational studies. By the early 1990’s, social scientists had made major contributions to the body of knowledge regarding the subject of human relationships; for example, the primacy of attachments and the consequences of
deprivation and disruption has been established with observational and empiric data (Baumeister & Leary, 1995; Hazan & Shaver, 1994).

Hawkley, Browne, and Cacioppo (2005) reported on sequential studies of how humans make meaning of their social relationships. Their results suggested feelings of social isolation may derive from the absence of “emotional” or “social” connections with others. In the first study, researchers analyzed the responses from 2,531 college undergraduate students (1,198 male, 1,315 female, and 18 undeclared) to describe perceptions of loneliness and social connectedness using the R-UCLA Scale (Russell, Peplau & Cutrona, 1980). The exploratory and confirmatory factor analyses resulted in a three-factor representation of loneliness-connectedness whereby the individual factors (isolation, relational connectedness and collective connectedness) were subsumed under the overarching construct loneliness. From this structure, the authors derived three subscales from items in the R-UCLA Scale to represent isolation, relational connectedness and collective connectedness. These subscales demonstrated acceptable internal consistency and reliability with Cronbach’s alpha ratings of .81, .87, and .76, respectively. That the different aspects of loneliness-connectedness were subordinate to the overarching concept was demonstrated by the intercorrelations among the factors ($r = -0.69$ to 0.55 in the exploratory factor analysis; $r = -0.80$ to 0.73 in the confirmatory factor analysis).

Isolation was described as a pervasive sense of social dissatisfaction at the personal level, represented in the subscale by items reflecting feelings of
aloneness, rejection, and withdrawal. Relational connectedness was described as an individual’s social satisfaction at the interpersonal level; items on this subscale acknowledge feelings of familiarity, closeness, and support corresponding to the idea of a relational social self, as described by Brewer and Gardner (1996). Finally, items representing the factor collective connectedness deal with feelings of group identification and cohesion corresponding to the idea of a collective social self. The results of the factor analyses from this first study were consistent across genders for the undergraduate study population.

In the second study, the authors sought to determine whether the fit of the three-dimensional structure identified in the first study would generalize to a sample of community-dwelling older adults, presumably at very different points in their lives individually and socially. A second goal of this study was to determine predictors of the three factors representing loneliness-connectedness as the authors hypothesized a three-dimensional structure of social meaning-making. From a population-based sample of 197 participants who completed the R-UCLA Scale (Mage 57.5 years [SD 4.4 years]; 100 females, 97 males; 77 whites, 66 African-Americans, and 54 Hispanics), confirmatory factor analysis yielded a root mean square error of approximation (RMSEA; an index of statistical fit [Browne & Cudeck, 1992]), of 0.057 (90% CI = 0.044–0.069), supporting the three-factor representation of the construct loneliness-connectedness which was consistent across ethnicity and gender.
Further analysis of subscale responses pointed to several predictors of loneliness in adults: being married or living with a partner predicted lower Isolation scores ($\beta = -0.76, p = .023$), while the number of friends and relatives predicted lower levels of isolation among the non-married ($\beta = -0.10, p = .021$) but not among the married ($\beta = -0.03, p = .495$). Relational connectedness scores did not differ as a function of marital status, but were predicted by regular contact with a greater number of close relatives and friends ($\beta = 0.11, p < .001$), by a greater number of group memberships ($\beta = 0.21, p = .002$), and by religious affiliation ($\beta = 0.63, p = .037$). However, when controlling for the effects of all covariates in their model, the only unique predictor of relational connectedness was the number of close friends and relatives with whom participants spoke regularly ($\beta = 0.043, p = .026$). There was an interaction effect between marital status and age ($\beta = 0.11, p = .024$) whereby feelings of relational connectedness decreased with age among the nonmarried, but did not change with age among the married. The last factor within the construct loneliness, collective connectedness was not significantly related to marital status, but was predicted by the number of close relatives and friends ($\beta = 0.10, p < .001$), number of group memberships ($\beta = 0.30, p < .001$), and by whether or not one reported a religious affiliation ($\beta = 0.71, p = .02$). However, when analysis controlled for the effects of all covariates, the only unique predictor of collective connectedness, satisfaction with relationships at the group level, was the number of group memberships ($\beta = .016, p = .002$). Thus, the proposed three-factor structure representing and
influencing the construct loneliness-connectedness was relevant for both college-age students and older adults. Further, it appears that individual factors are predicted by regular contact with friends and family, whether a person lives alone or with another person, and how involved a person as a member of a community group or religion. These influences, particularly regular contact with friends and family, become vulnerable during chronic critical illness.

From a nursing perspective, the study of human relationships also has a long tradition, with a focus on the role of interpersonal relationships in promoting healing and optimal wellness in the context of health care delivery. Hildegard Peplau theorized that a major function of the nurse-patient relationship is to facilitate and promote patient independence to act on his or her own behalf to impact healing and health (Reed, 2005, p.490). How a nurse manages a CCI patient’s contact with friends and family for optimal impact upon his or her overall comfort and health-seeking behaviors is not known.

Participants in Bergbom and Askwall’s hermeneutic study (2000) of intensive care unit (ICU) patient’s perceptions of the value of relationships during their illness (n = 5; M_age 53.6 years, range 39-67 years; 3 male, 2 female; ICU length-of-stay 5 days - 8weeks) stated that the presence of those with whom they felt close and could trust provided them with a feeling of security, protection, and advocacy within the system; the presence of those ‘nearest and dearest’ to them, therefore, was perceived as important for survival and recovery. In addition, participants expressed the belief that contact with close
family and friends supplied them with an ongoing sense of belonging within his or her social network; they felt they had not, and would not, be abandoned. This sense of non-abandonment facilitated hope for the future and kept participants from having negative thoughts about suffering or death. Although this was a small sample, the insights provided by participants warrant future investigation about the potential influence of relationships during critical illness and recovery.

In an in-depth qualitative study of the meaning of interpersonal support for the critically ill patient (n = 30; M_{age} 55.0 years, range 31-72 years; 14 male, 16 female), Hupcey (2001) interviewed patients while they were in the ICU. She concluded that the quality of support, in terms of visitors and staff maintaining a positive outlook, being dependable, and sometimes praying for or with the patient, was more important than the actual number of visitors a patient had during their stay. Respondents’ text focused on the themes of perceptions of helpfulness, primarily in the form of having a close family member or friend with them at all times. Those respondents who felt inadequately supported during their illness were openly critical of both family and ICU staff, suggesting patients want and need support from personal contacts as well as professional care providers.

The previous two studies’ findings describe only positive consequences of the presence of family or friends in the ICU, but recent findings by Fredriksen and Svensson (2010) and others warrant consideration. The six participants in their phenomenological hermeneutic exploration of critically ill patients’
experience of the physical presence of significant others revealed positive and negative consequences. Positive consequences included feelings of belonging and motivation to recover, when family was physically present. Negative emotional consequences were described as worry over family members’ reactions and needs. Similarly, Olsen, Dysvik and Hansen (2009) reported critically patients prefer visitors be restricted to close family or friends and that some limits on length of visits be imposed to minimize worry over family members’ reactions and stress.

In a small study of fatigued women (n=17; Mage 38.5 years, SD 7.4 years) who were otherwise healthy (Dzurec, 2000), participants who tended to personify the state of relatedness known as disconnectedness (uninvolved and uncomfortable) (n = 14) also described a spiraling emotional absence, lack of energy and motivation, and depressive symptoms, more so than fatigued participants whose state of relatedness was other than disconnectedness. The three subjects who experiences were interpreted as the relatedness state of parallelism (uninvolved and comfortable) were less vulnerable to the negative influences of their fatigue, such as lack of motivation to be physically active and depressive symptoms. Those who personified a state of parallelism were more likely to take an active role in managing their fatigue symptoms.

Patusky (2002) conducted an analytical follow-up of that study to examine the fit between the Theory of Human Relatedness and Dzurec’s findings. She confirmed the characterizations of the four states of relatedness set forth in the
theory – connectedness, disconnectedness, parallelism, and enmeshment – noting that disconnectedness was particularly distressing and dissatisfying to participants, while parallelism served as a protective mechanism that allowed them to conserve energy to maintain a focus on improving their health. These findings suggest that distress experienced within relationships, a state which may inhibit comfort, may reduce the likelihood of a person acting on his or her own behalf to optimize health.

The Theory of Human Relatedness informed Choenarom, Williams, and Hagerty’s (2005) longitudinal study of the role of sense of belonging, social support, and spousal support on the relationship between perceived stress and symptoms of depression in individuals with a history of depression (n = 51), compared to those with no prior history of depression (n = 39). In the combined sample, there were 27 males and 63 females; M_{age} 38.8 years (SD 14.0 years); 89% were white and 11% were from other ethnic/racial backgrounds. There were no significant demographic differences between the depressed group and the comparison group.

Data were obtained upon entry into the study and 3, 6, and 9 months after enrollment. Repeated measures analysis showed that increased perceived stress and lower sense of belonging had significant direct effects on the severity of depression ($t = 3.62, p = .002$ and $t = 2.89, p = .011$, respectively) in those with a history of depression. An alteration in sense of belonging, something not
uncommon during a prolonged critical illness, can have important implications for mental health and well-being.

In Maddox, Dunn, and Pretty’s study (2001) to identify and explore factors influencing patients’ perceptions of the recovery period following a critical illness, the role of family and friends was considered central to his or her recovery. Participants (n = 5 patients and 4 caregiver/significant others; Mage 59.6 years, range 42-76 years) completed a semi-structured interview 6 to 15 weeks following ICU discharge. This interview timeframe was designated based upon literature that identifies a ‘healing’ phase during which patients, having stabilized, feel more secure and confident and are better able to reflect upon the meaning(s) of their experiences (Welch, 1995; Granberg, Engberg, & Lundberg, 1999). Although patient participants expressed concern for the impact their illness would have on family and friends, it was family members and friends who were most often credited with helping patients maintain the positive mental attitude necessary to deal with challenges – expected and unexpected – during a sometimes prolonged recovery period. In this small pilot study all but one respondent reported a strengthening of bonds following life-threatening experience. The influence of relationships during critical illness can be realized during and long after the illness episode. There remains a great deal about the role of relationships, and their potential benefits to patient comfort, during chronic critical illness that is not known.
Comfort

Comfort is a primary goal of all nursing care (Kolcaba & Kolcaba, 1991). It has long been considered a component of effective nursing, as evidenced by the inclusion of the subject in nursing textbooks such as those of Harmer, published in 1926, Goodnow, published in 1935 (Kolcaba & Kolcaba, 1991) and more recently, Black and Hawks in 2005 (7th Edition). Campbell’s second edition of Nursing Diagnoses and Intervention in Nursing Practice (1984) classified comfort in the contexts of illness and wellness, indicating it is a matter of importance throughout our lives. Despite its presence in academia and practice as a primary goal of nursing care, comfort as a defined and measured outcome is not readily visible in the literature (Novak, Kolcaba, Steiner & Dowd, 2001), and is even less so for the critically ill patient population. For that reason, the literature presented in this paper will expand on comfort to include symptoms experienced by critically ill patients. Although there are a number of studies that employed a quantitative design, the bulk of research to date has been qualitative and exploratory.

With their initial concept analysis, Kolcaba and Kolcaba (1991) established the historical and contemporary foundations of comfort as it relates to nursing care. Subsequent work explored the taxonomy of comfort (Kolcaba, 1991), measurement of comfort as an outcome of nursing care (Kolcaba, 1992), and, finally, formally presented it as a middle-range theory (Kolcaba, 1994; Kolcaba,
2001; Kolcaba, 2003) upon which researchers could meaningfully contribute to nursing’s body of knowledge and practice innovations.

In an investigation of the effects of healing touch (HT), one-on-one coaching, and an intervention that combined HT with one-on-one coaching, Dowd, Kolcaba, Steiner, and Fashinpaur (2007) sought to improve comfort and stress-reduction in younger college students, a population particularly vulnerable to negative consequences of life transitions in terms of interfering with healthy behavior, ability to cope effectively with stress, and overall feelings of well-being (Dowd, Kolcaba, Steiner, and Fashinpaur). Research staff recruited undergraduate students who self-identified as having multiple stressors and related symptoms; those with any previous history of psychiatric disorders, migraines, or who were already in treatment for stress, or more than 25 years old were excluded.

Volunteers for the study were randomly assigned to one of three experimental groups, or a control group. Enrollment consisted of 12 participants who received HT, 14 who received coaching, and 13 who received a combination of the two; the interventions were administered weekly over the course of three weeks. Thirteen participants served as the control by being on a waiting list to receive the interventions at the conclusion of the study. The sample was comprised of 12 men and 40 women, and 71% were white (M<sub>age</sub> 20.8 years, SD 1.9 years). Comfort and stress-related symptoms were assessed using the 35-item Healing Touch Comfort Questionnaire (Dowd, Kolcaba & Steiner, 2006) and the
26-item Stress Test (Yarnell, 2005) at four time-points: baseline, before the first intervention, immediately before the third interventions, and one week after completion of the treatment protocol. Brief comfort and stress rating scales were also completed immediately before and after each intervention.

At baseline, there were no statistically significant differences between groups on comfort ($F = 1.46, p = .23$) and stress ($F = 1.29, p = .29$). All of the treatment groups experienced significantly increased comfort levels compared to controls ($F = 4.27, p = .01$) during the study, and for an additional week after the final intervention ($F = 4.55, p = .00$). The greatest increases in comfort scores occurred in the HT group at each time point. Differences in improvement in comfort across the different interventions were not statistically significant. The decreases between pretest- and posttest-related stress symptoms for each intervention were also significant ($p < .000$), with the greatest decreases occurring for the HT group at each time point.

In summary, the interventions of HT, coaching, and a combination of the two were all significantly effective in increasing comfort and reducing stress-related symptoms in comparison to the control group. Although this was a small study, the findings suggest that interpersonal activities designed to improve comfort may influence healthy behavior and feelings of well-being in people experiencing difficult life situations, such as the CCI.
The application of the concept of comfort in nursing research is slightly different in Li and Puntillo’s (2006) pilot study exploring the experiences of nine frequently reported symptoms of ICU patients. In their study, particular states or experiences of discomfort were the focus, with results casting new light on nurses’ need to renew their commitment to promoting comfort in this patient population. The symptoms studied were pain, dyspnea, thirst, nausea, hunger, tiredness, anxiety, generalized discomfort, and depressed feelings. Their participants (n=15) were ages 31-80 years (Mage 63.0 years); 7 were male, 8 female; all were white. Two participants were admitted to the ICU with a medical diagnosis, and 13 were either surgical or trauma patients. All subjects were interviewed while in the ICU, and the length of stay at the time of interview ranged from 3 to 31 days (Mage = 11.7 days). Participants’ average duration of mechanical ventilation was 6 days (SD 4.0 days). Analgesics and anxiolytic agents administered within 24 hours prior to interview were noted and included morphine sulfate, midazolam, and lorazepam.

A numeric rating scale for each symptom was used to evaluate both the prevalence and intensity of each symptom; possible scores ranged 0-10, where 0 = none and 10 = worst. There was 100% prevalence of the symptoms assessed; the most common symptom experienced was dyspnea (100% of participants), the least common was nausea (66.7% had none). General discomfort was experienced by 83% of the participants; 66% scored the intensity between 4 and 6 (mean 4.9, SD 2.3), indicating a moderate degree of discomfort. The remaining
symptoms assessed, in rank of prevalence, were: anxiety (87%; mean 4.5, SD 2.9); tiredness (87%; mean 5.0, SD 3.0); thirst (80%; mean 5.7, SD 3.7); hunger (74%; mean 4.3, SD 3.7); pain (60%; mean 2.8, SD 3.1); and depressed feelings (60%; mean 2.6, SD 2.7).

Statistical relationships that reached a significance level of < .05 were feeling tired and being anxious ($r = .79$), being thirsty and feeling tired ($r = .79$), general discomfort and feeling tired ($r = .74$), being hungry and being thirsty ($r = .58$), being thirsty and feeling anxious ($r = .54$), general discomfort and being thirsty ($r = .52$), and depressed feelings and dyspnea ($r = .52$). It is logical to conclude that achieving comfort during an ICU stay can be a challenge, raising the importance of the study of factors that influence and are influenced by comfort, such as relationships and therapeutic physical activity, to an even higher level.

Li and Puntillo’s findings are echoed in Roberts, Rickard, Rajbhandari, and Reynolds’ (2007) multi-center, prospective, cohort exploration of ICU patient’s long-term recall of factual memories of their ICU stay. The sample was comprised of 41 subjects, 18 who experienced delirium and 23 who did not. Data from respondents who experienced delirium were compared to those who did not experience delirium. Both groups had factual memories of their ICU stay, although the non-delirious group had significantly more than the delirious group (96% vs. 67%, $p = .035$). Themes described by respondents largely focused upon matters pertaining to procedures, staff, visitors, events, and comfort. Main
comfort-focused messages related to feeling frightened, being thirsty and being in pain, feeling secure and feeling really peaceful. The other themes contained messages that could also be linked to the experience of comfort or discomfort. For example, the comforting touch of a nurse, the unpleasant experience of an indwelling urinary catheter, being defibrillated, and chest tube insertion were all commonly mentioned by respondents. The majority of messages gave an indication that the ICU experience was primarily negative. The messages of comfort provide evidence that relationships and connection with others play an important role in memories of comfort.

A study by Gardner, Elliott, Gill, Griffin and Crawford (2005) describes the patient experience of comfort and companionship during critical illness. This was a small, exploratory qualitative study, undertaken as part of a larger triangulated project examining pain and health status of patients following cardiac surgery. The aims of the study were to explore participants’ memories of their hospitalization period, and perceptions of their recovery during the 6 months after cardiac surgery. Semi-structured interviews were conducted with 8 subjects purposively recruited to obtain gender equality and thematic saturation. Subjects were 29 to 85 years of age (M_\text{age} 75 years), four male and four female. Mean total ICU length of stay was 3.5 days (range 1-8 days); subjects were consented during their index hospital stay and interviewed in person 6 months after discharge from the hospital. Four subjects had more than one ICU and/or
hospital admission; these interviews were conducted 6 months after their last admission.

Seven themes emerged from the data: (1) impressions of ICU; (2) comfort/discomfort; (3) being sick/getting better; (4) companionship/isolation; (5) hope/hopelessness; (6) acceptance/apprehension; and (7) life changes. A number of themes demonstrated a continuum of experiences; comfort/discomfort was one such theme where subjects’ perceptions demonstrated a wide range of experiences. In terms of a conceptual definition, comfort was viewed as an apparent absence of pain. Most subjects described their “comfort” experience relative to the physical discomforts of having an endotracheal tube in place, post-operative incision pain, or, in one case, exacerbation of chronic hip pain due to enforced immobility. This is consistent with others’ exploration of symptoms commonly experienced during an ICU stay (Li & Puntillo, 2006).

The theme of companionship/isolation emerged from comments regarding the reassuring presence and vigilance of staff and the companionship of other patients in the open-ward ICU. Some comments suggested that contact and interaction with others experiencing similar circumstances provided motivation to “get better” and a sense of improved morale. Conversely, those who had been in a private room following their ICU stay mentioned fear and a “sense of being locked away”, although one participant did state that “the peace and quiet” were enjoyable.
These findings point to a common experience of recalling ICU events and feelings experienced during illness that influence and are influenced by feelings of comfort or discomfort and interactions with others in the patient’s environment.

**Health-seeking behaviors/Therapeutic Physical Activity**

The undesirable consequences of prolonged bed rest and immobility in adults are well-described in the literature (Chobanian, Lille, Tercyak, and Blevins, 1974; Creditor, 1993; Brown, Friedkin, and Inouye, 2004; Timmerman, 2007). Many of these consequences threaten to compound dangers inherent in a prolonged critical illness. In a pilot study conducted to evaluate the feasibility and accuracy of actigraphy to measure therapeutic activity in 20 CCI patients (8 male, 12 female; Mage 59.8 years, SD 16.45 years) over the course of an eight-hour observation period, Winkleman, Higgins & Chen (2005) found that participants experienced infrequent activity and short durations of therapeutic activity, most often in the form of turning or range-of-motion exercises initiated by the registered nurse (average 3 activities/8 hours; average 11 minutes, SD 6 minutes). Despite physiologic stability, only two subjects sat in a chair and none of the subjects were assisted to dangle at the bedside or ambulate.

Evidence supplied by Brown, Friedkin, and Inouye (2004) highlights the gravity of such an approach to patient management. Their prospective cohort study of 498 elderly patients (Mage 78.7 years, SD 6.1 years; 56% female) found that those who had lower levels of mobility while hospitalized experienced
significantly higher rates of in-hospital functional decline and death compared with those who had high levels of mobility (65% versus 15%, and 24% versus 1%, respectively; \( ps < .001 \)). Low and intermediate activity levels accounted for 48% of the sample studied. Reasons cited for low mobility were often independent of a patients’ illness acuity, or pre-hospital functional ability.

Although not all CCI patients are elderly, these findings, considered in light of Winkleman, Higgins, and Chen’s work (2005), suggest that there is a need to elevate patient activity as a priority in the ICU setting in an effort to offset unintentional complications which could prove deleterious to treatment goals. Promotion of therapeutic physical activity takes on further importance when we consider that CCI patients mostly “want to survive the critical illness and to quickly recover without significant lasting damage or loss of function or quality of life” (Nierman, 2002, p. 486). This statement is echoed by professional rehabilitation specialists, whose mission is “to improve the quality of the client’s life through improving functional ability” (Jacelon, 2001, p.370).

Mayer-Oakes, Oye, and Leake (1991) published some of the first data regarding the relationship between functional status and outcomes in older ICU patients where analysis controlled for acute and chronic illness severity. The purpose of their study was to examine age and pre-admission functional status as potential predictors of hospital and 6-month mortality in older Medical Intensive Care Unit (MICU) patients. The sample was drawn from three community hospital MICUs and consisted of 398 patients aged 50 years and
older purposively recruited to obtain an equal number of participants among three age groups (36% were 50-64 years old, 26% were 65-74 years old, and 38% were ≥ 75 years old; 51% of the patients studied were female). There were no significant differences in demographic characteristics or in ICU, hospital, or 6-month mortality between patients with and patients without functional status information.

Assessment of pre-admission functional status was dichotomous: limited or not limited. Of the 227 patients who had functional status data, 42% were limited. Not surprisingly, there were significant associations between age and functional impairment, age and hospital length of stay, and age and prior hospitalization. A finding of interest was the interaction between age and functional status such that older individuals (age group ≥75 years old) with pre-admission functional limitation were more likely to experience either in-hospital or 6-month mortality ($r = 1.787, p < .01$ and $r = 1.53, p < .001$, respectively) than any other age group, with or without functional limitation. Acute Physiology Score was the only other variable to be significantly associated with mortality at both time points ($r = .196$ and $.120$, respectively, $p < .001$). For older MICU patients, the presence of a pre-admission limitation of functional status increases the risk of mortality within 6 months, emphasizing the importance of facilitating therapeutic physical activity during and after illness as a possible way to offset the possibility of an adverse outcome.
Lipsett and colleagues (2000) explored factors influencing survival and functional outcome after prolonged ICU stay using the Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter & Gilson, 1981) score as a measure of functional outcome. The SIP is a multidimensional, cumulative health index consisting of 136 questions divided into 12 categories. These categories are grouped into five dimensions; dimensions of interest for this study were the Physical (ambulation, mobility, and body care) and Psychosocial (social interactions, alertness behavior, emotional behavior, and communication) dimensions. Total SIP scores range from 0 to 100. The general adult population has a SIP score of approximately 5, while a score of 20 indicates a need for substantial daily care and a score greater than 30 corresponds to a need for almost complete care.

Surgical Intensive Care Unit (SICU) patients with a length of stay more than 7 days were consecutively enrolled over a 12-month period of time (n = 127). SIP scores were measured at baseline and at 1, 3, 6, and 12 months. The average age of enrolled patients who were alive and responded at 1-year post ICU (n=47) was 56 years (SD 12 years); 32 male and 15 female, with a mean Acute Physiologic and Chronic Health Evaluation score (APACHE II) on admission of 21.0 (SD 6.5). There was a 46% survival rate one year after admission to the study ICU. The study population did not differ in age, sex, or survival from the SICU population at large. The APACHE II score on admission predicted survival at one year; non-survivors had a significantly higher APACHE II score (mean 25.8 ± 5.9) than survivors (mean 20.8 ± 6.3, p=.001). The
median SIP score among survivors was 20.2 at baseline, 42.9 at 1 month, 36.2 at 3 months, and 20.3 at 6 months, and was lower than baseline at 1 year. The patient diagnoses did not significantly influence the baseline SIP and at no time during the study did diagnostic group significantly influence the total SIP score. At 1 year, the overall SIP score and both physical and psychosocial scores were significantly less than at baseline. Early in the illness, the physical component of the SIP dominated, whereas the psychosocial aspects of the illness were more long-lasting.

Measures that have been used to characterize CCI patients and their functional outcomes include the Therapeutic Intervention Scoring System (TISS) (Martin, Hill, Burns & Chen, 2005), the Sickness Impact Profile (Lipsett, et. al., 2000), and the Karnofsky Performance Scale Index (Ulvik, Kvåle, Wentzel-Larsen & Hans Flaatten, 2007), however these measures may not be sufficiently sensitive to the often small, but important, gains that patients make on the road to recovery from chronic critical illness. The Functional Independence Measure (FIM) is a tool that measures cognitive and motor function; frequently used in rehabilitation settings. Although it has not been widely used to characterize CCI patients or their outcomes (Chiang, Lang, Wu, Wu & Wu, 2006), the FIM is particularly relevant for the CCI, as its sensitivity will detect small gains (Jette, Haley & Ni, 2003).

Chiang, Wang, Wu, Wu and Wu (2006) conducted an intervention study in a small sample of hemodynamically stable patients receiving prolonged
mechanical ventilation (> 14 days) to test the effects of physical training on functional abilities and patient outcomes. Seventeen patient-participants comprised the treatment group (12 males, 5 females; $M_{age} = 75$ years, range 63-83 years) and there were fifteen participants in the control group (12 males, 3 females, $M_{age} = 79$ years, range 72.5-82.5 years). The average duration of mechanical ventilation at baseline was 46 days for the treatment group (31-81 days) and 52 days for the control group (23-81 days). All participants were routinely evaluated for protocol-directed weaning independent of the study procedures. There were no significant baseline differences between the two groups. Functional ability was measured using the FIM total and subscale scores and patient outcomes were measured in terms of the number of ventilator-free days.

The treatment consisted of physical training with a licensed physical therapist 5 days a week for 6 weeks. Exercises consisted of upper and lower extremity gravity-resistance range-of-motion (ROM), which, in some subjects, progressed to use of weight-resistance (maximum 1.3 pounds), respiratory muscle retraining, and bedside functional retraining, which included rolling from side-to-side on the bed, transfers to/from bed, chair, and wheelchair, and coming to a standing position. Nurses and staff were verbally encouraged by the therapists to promote these exercises between sessions, but there was negligible follow-through.
The treatment group had significantly higher total FIM scores at each interval, compared with their baseline \((p < .05)\) and compared with control group \((p < .05)\). Gains made by the treatment group between the 3rd and 6th week were also significant \((p < .05)\). Although not statistically significant, there was a trend toward deterioration in the control group, with lower total FIM scores at the 3rd and 6th week. For treatment group, ventilator-free time was significantly correlated to changes across time in both the ADL subscale scores and the Mobility subscale scores \((r = .84 \text{ and } r = .81, \text{ respectively}; p < .05)\). All subjects enrolled in the study were unable to walk at baseline; after six weeks of physical training, 53% of the treatment group had improved to the point of being ambulatory. In this unique study focusing on the functional abilities of the patient on mechanical ventilation for a prolonged period, the benefits of regular and frequent physical training were evident. It may be important to understand what influences a patient in his or her participation of therapeutic physical activity as soon as hemodynamic stability is achieved.

These studies suggest the importance of functional ability to the CCI patient as an outcome that warrants attention throughout the patient’s illness and recovery. As pointed out by Scheinhorn, Chao, and Stearn-Hassenpflug (2002), results of functional status studies and quality-of-life (QQL) measures are now being reported in small studies of patients undergoing prolonged mechanical ventilation. These results are increasingly as important as weaning
outcome, disposition, and survival data, as they accumulate to give a more precise picture of the treatment results in this population.

**Relationships and Comfort**

A primary motivation for close attachments is comfort (Hazan & Shaver, 1994; Bowlby, 1954). Research that has supported this statement has employed both qualitative and quantitative methodologies. Johnson’s (2004) qualitative study focused on the theme of “reclaiming the everyday world” (p.190) in her follow-up analysis of data from a Heideggerian exploration of ICU patient’s experience of being mechanically ventilated over an extended period (Johnson, St. John & Moyle, 2006). The nine participants included in the study (6 male, 3 female; ages 21-69) described a process of re-engaging with their environment, gaining comfort through families and staff, seeking a sense of control over treatments and their environment, attempting to communicate, questioning and interpreting their environment, and re-claiming self.

Re-engaging was defined as feeling connected in a meaningful way to other people within their environment and gave them a sense they were making positive progress towards recovery. Interestingly, it was the simple presence of staff and families that was considered the most influential act of comfort for them.

Another qualitative study that described the role relationships may play for patients during critical illness was conducted by Hupcey (2000); this publication described one aspect of a larger investigation that explored the ICU
experience from a patient perspective (Hupcey & Zimmerman, 2000; Hupcey, 2001). Hupcey focused on the psychosocial needs of ICU patients using grounded theory development in open-ended, unstructured patient interviews, once the patient was considered “stable”, either still in ICU or immediately after transfer. She began with the grand-tour question “tell me about your hospitalization” and probed for additional detail by asking participants “what helped most during ICU stay? What was upsetting?” The sub-sample studied was comprised of 45 critically ill patients (Mage 59 years; range 25-80 years; 20 male, 25 female) from medical or surgical ICUs; ICU length of stay was a minimum of three days, with some greater than 30 days.

The overarching theme respondents communicated was the need to feel safe; this was something they described as being greatly influenced by the presence of family and friends, staff actions, and their own religion and faith. Regarding family and friends specifically, respondents conveyed that, even if their visitor was not talking with them, they felt a sense of comfort. Visitors also contributed to feelings of hopefulness, encouragement, connection to the world outside of the ICU, and a desire to fight to get better. Conversely, when family and friends were not present, respondents described feelings of distress. Similarly, if family or friends were seen visibly upset or crying, respondents were more likely to feel a sense of doom, hopelessness, or discouragement. Nursing staff also impacted those perceptions; the predominant theme was that nurses provided the respondents with a feeling of being watched over, of having
a shoulder to cry on. On other hand, when a nurse was feeling stressed and somehow conveyed that to patient in terms of being short or impatient, respondents described feeling distressed. These findings suggest that relationships can influence patient comfort positively and negatively.

Williams and Irurita (2006) qualitatively studied the perceived therapeutic effect of interpersonal interactions experienced during hospitalization. Purposive sampling was used in the selection of participants who had been hospitalized for a variety of medical and surgical reasons. The sample consisted of 40 patient participants who provided a total of 36 formal interviews and 4 informal interviews. Data also included 78 hours of field observations of specific patients interacting with nurses over several days. Documentation related to the patients who were observed was also reviewed, and informal interviews were conducted with 32 nurses. Most of the participants were still recovering from their illness at the time of the interview. Some were interviewed during their hospitalization, others within a few weeks of discharge from hospital; some of the participants were included because their recall of an episode of hospitalization, though not within the preceding year, was vivid and easily described.

Their grounded theory development provided a description of the context of emotional comfort and insight into the therapeutic effect of this dimension of patient care. Patient participants commented that, when nurses approached them “as a whole person”, considering the psychological needs as important as the physical needs, they experienced greater emotional comfort, which lessened their
physical discomfort. Similar to findings by La Guardia, Ryan, Couchman and Deci (2000), satisfaction of needs within interpersonal relationships influences the experience of well-being in the form of both emotional and physical comfort.

Analysis of data revealed that patients attributed more importance to their emotional comfort than their physical comfort because of an underlying perception that the consequence of emotional comfort was a decrease in physical discomfort. One patient stated the interpersonal interactions of nurses had made her feel better, both physically and psychologically. Conversely, emotional discomfort was perceived to hinder most patients in their recovery. However, some patients used their emotional discomfort as motivation to engage in recovery-promoting activities, such as physical therapy, and activities of daily living.

Using a quantitative design, Rotondi and colleagues’ (2002) describe the stressful experiences of adult patients who received mechanical ventilation for at least 48 hrs in an ICU. This prospective cohort study was set in four ICUs within an East Coast tertiary care university medical center. There were 150 subjects consented, 100 of whom had vivid recall of their mechanical ventilation and ICU experiences and thus were included in the overall analysis (\(M_{age} 53.2\) years, SD 19.9 years, median 52 years; 47 male, 53 female). The authors reported on responses to a 32-item questionnaire focusing on patients’ stressful experiences, both psychological and physical, associated with the mechanical ventilation endotracheal tube and with being in an ICU.
Physical experiences that were reported as stressful were trouble speaking (78.1%), being thirsty (76%), being tense (66%) or not being in control (55%). Those of a psychological nature involved the maintenance of relationships; these were missing spouse and/or friends (42%), and feelings of loneliness (39.6%). The researchers also analyzed associations between paired psychological and physical experiences that subjects considered bothersome and found significant associations between feeling nervous when left alone (a psychological experience) and the occurrence of spells of terror (\( \gamma = .863 \)), discomfort of endotracheal tube (\( \gamma = .810 \)), and feeling something bad will happen (\( \gamma = .806 \)). These findings support earlier statements that the ICU experience is largely negative, and provide evidence that supportive relationships, those whose state of relatedness is characterized by a resulting perception of well-being, may play a role in affecting patient comfort.

**Relationships and Health-seeking Behaviors**

What influences an individual to engage in behaviors that may promote his or her recovery from any illness is not always clear. Most likely, sources of motivation are complex and somewhat unique to the individual. Studies presented here focus on the influences of an individual’s relationships and states of relatedness upon health-seeking behaviors, especially those of a physical nature (e.g., rehabilitation).

Evenson, Rosamond and Luepker (1998) analyzed data on 3,841 patients (58% male; 96% white) enrolled in the Minnesota Heart Survey Acute Myocardial
Infarction Registry from 1990 to 1993 as part of the Minnesota Heart Survey, a long-term cardiovascular disease surveillance project. Their objective was to describe population patterns of outpatient cardiac rehabilitation utilization and identify factors predicting its use. The sample was comprised of 1080 patients with myocardial infarction (MI), 1070 patients with angina, and 1691 patients "ruled-out" for MI that were discharged for other reasons. Although overall participation rates were low, respondents who were married were significantly more likely to participate in rehab program than those who were not married (52% among those with MI, \( p < .001 \); 26% among those with angina, \( p < .001 \)).

King, Humen, Smith, Phan and Teo (2001) recruited 304 adult patients (76% male, 24% female; 69% < 70 years old, 31% \( \geq 70 \) years old) who had been hospitalized for MI and/or coronary artery bypass graft surgery (CABG) to examine the relationships among patients’ demographic (sex, age) and psychosocial characteristics (self efficacy expectations, behavior performance, self-motivation, and social support) and their attendance at outpatient cardiac rehabilitation programs. In this study, social support was defined in terms of the numbers of contacts in an individual’s network as well as perceived benefits from the network members.

Data were collected at two weeks and six months following their cardiac event. Using repeated measures analysis of variance, the authors concluded that neither self-motivation nor social support predicted cardiac rehabilitation attendance, although the external validity of the findings was limited because of
the voluntary nature of subject participation and attrition (36%) over the six month follow up. Still, these results are contrary to a number of studies that demonstrated correlations among social support and cardiac outcomes, cardiac rehabilitation attendance (more so for women than men), and sustaining healthy behavior (Blumenthal, Williams, Wallace, et al., 1982; Sallis, Hovell & Hofestetter, 1992; Cohen, 1988). This study illustrates the complexity of influences on an individual’s engagement in health-seeking behaviors and further emphasizes the importance of studying this in the CCI population.

The community setting has produced interesting research regarding the influence of relationships on health-seeking behaviors such as participation in group exercise programs. Dungan, Brown and Ramsey (1996) used an experimental, repeated-measures design to measure outcomes of a health maintenance program (HMP) of regular exercise, health teaching and group participation on physical and mental well-being in a convenience sample of frail older adults living independently. The intervention consisted of 90-minute sessions conducted three times weekly for 6 months; 60 minutes of professionally-led exercise (stretching, flexibility) and 30 minutes of group discussion, led by a health professional, on topics such as nutrition, relaxation techniques, stress management, art and music appreciation. The authors posited that, in group interactions, an emphasis is placed on effective communication and sharing concern for others and self; in so doing, participants maintain positive self-esteem and life satisfaction.
The sample (n=59) was 34% male and 66% female; participants were between the ages of 61 and 93 and had at least one chronic illness. Outcomes were evaluated pre and post-intervention and consisted of life satisfaction and self-esteem self-report questionnaires, blood pressure comparisons, improvement on range of motion for bilateral ankles and shoulders, and measurement of hand strength. There was a significant drop in mean systolic blood pressures ($t = 2.69, p=.01$); ankle range of motion all showed increases which the authors consider clinically significant and corresponded to therapists’ observations of improved stability, although only right ankle range of motion improvement was statistically significant. Similarly, increases in right and left hand strength were considered clinically significant, but did not reach statistical significance.

In addition to physical improvements, there were significant improvements in the life-satisfaction scores and the self-esteem scores, as measured on a 100-millimeter visual analog scale ($t = 4.6, p <0.001$ and $t = 3.3, p <0.002$, respectively). Evaluations written by the participants following the final session included the following comments, suggestive of the psychological benefit of group interaction: “I feel better all over, thanks.” “Wonderful new friends who love each other and love to exercise!” “My mind, body and soul feel better. Thanks to exercise and group” (Dungan, Brown & Ramsey, 1996, p.1192). These findings lend support to the study with evidence of associations between relationships, physical activity and well-being.
Finally, a recent study by McAdam, Arai, and Puntillo (2008) described previously unacknowledged contributions to care that family members perform while their loved one is at high risk of dying in the intensive care unit. The study was conducted in two intensive care units at a tertiary medical center in the western United States and used an exploratory design and descriptive analyses. Participants were recruited using purposive sampling in order to represent a variety of ICU patients and diagnoses; researchers interviewed 25 family members of 24 ICU patients at high risk of dying. High risk of dying was defined by either an ICU length of stay $\geq 3$ days, attending physician confirmation of likelihood of death, and/or more than one organ system failure. Interviews were conducted on a median of 8.5 days after the patient’s ICU admission. The sample was primarily female (60%) and white (84%), $M_{age}$ 52.6 years (SD 14.9 years). Participants were spouses (48%), parents (12%), daughters, (16%), and sons (12%). Patient ages ranged from 23 to 90 years, $M_{age}$ 59 years (SD 18.2 years).

Six distinct roles emerged from analysis of the transcripts: (1) Active presence, (2) Protector, (3) Facilitator, (4) Historian, (5) Voluntary caregiver, and (6) Coach. By maintaining an active presence at the bedside, vigil-like, family members believed that the patient “felt safer” and “more comfortable”. Acting as protector, family members responded to their own perceived need to take on the role of advocate and watchdog over their loved one’s care in the ICU. Activities described as facilitating included translating, explaining, and interpreting information for both the patient and the health care providers, while historians
used their knowledge of the patient’s prior medical status, history, and wishes to inform health-care providers. As a voluntary caregiver, family members described providing hands-on care to the patient, such as massaging, repositioning, and distracting him or her. The role of coach is particularly relevant to the study; it describes someone who motivates, comforts, and maintains hope in the patient during challenging situations. Family members believed they functioned as coaches when they offered support, encouragement, and understanding to the patient. These role descriptions reflect family members attending to the patient based upon their own desires, instincts, or needs. They reflect basic relationship drives to express care, provide safety, and support.

The authors describe advantages in terms of family outcomes, such as satisfaction, sense of control, and the opportunity for ongoing intimacy with the patient. Disadvantages are similarly described related to family and health-care providers concerns, and include the potential for stress, fatigue and guilt among and between family members and health-care providers. What is needed is a patient-derived response to these perceptions. How do patients perceive and benefit from family members efforts to contribute to care? How do these efforts influence patient outcomes such as comfort, engagement in health-seeking behaviors, sense of relatedness and its impact upon feelings of well-being?

**Comfort and Health-seeking Behaviors**

Kolcaba (1992) conceptualized holistic comfort as an immediate state of being strengthened as a result of perceived needs being met in any or all of four
contexts of the human experience (psychospiritual, physical, sociocultural, and environmental). The Comfort Theory (Kolcaba, 2003), and as a derivative, the study model, posit that being strengthened positively influences the likelihood an individual will engage in activities which promote recovery from illness. It is reasonable to expect, then, that a lack of comfort, physical or psychological, may deter from illness recovery.

Richmond, Kauder, Hinkle and Shults (2003) employed a prospective, correlational design to identify early predictors of long-term disability in 63 participants who experienced serious, non-central nervous system injuries (Mage 39.7 years, SD 16.9 years; 42 male, 21 female; average hospital length of stay 12 days, SD 13.5 days, range 3-95 days). The authors explored social network factors, age, functional ability prior to injury, and indicators of post-traumatic stress syndrome (PTSS) as possible predictors of long-term disability following traumatic injury requiring ICU care. Disability was described by the authors as “limitation in socially defined roles and tasks expected of an adult in a sociocultural environment” (p.197). Data collection was conducted at three intervals: during hospitalization, three months after discharge, and 2 ½ years after discharge. Measurement tools were the Network Subscale of a 6-item Social Support Questionnaire (based on the number of persons the patient thought he or she could turn to in particular circumstances) (Sarason, Levine, Basham & Sarason, 1983), and the 15-item Impact of Event Scale (Horowitz, Wilner &
Alvarcz, 1979), which measures two key elements of PTSS: intrusion behaviors and avoidance behaviors.

Thirty-six percent of the variance in the path analysis model was explained by the predictors of age, disability prior to injury, psychological distress at time of injury or soon after, and the incidence of short-term disability. There were no significant relationships between social network factors and long-term disability, contrary to other studies cited by the authors. However, there was a significant positive predictive relationship between psychological distress, discomfort, and long-term disability ($\beta = .607, p = .003$).

Findings from the Heart and Soul Study (Ruo, Rumsfeld, Hlatky, Liu, Browner, & Whooley, 2003) pertain to the potential association between comfort and health-seeking behaviors. Of the 1024 participants, 201 (20%) had depressive symptoms. Participants with depressive symptoms were more likely than those without depressive symptoms to report at least mild symptom burden (60% vs. 33%; $p < .001$), mild physical limitation (73% vs. 40%; $p < .001$), mildly diminished quality of life (67% vs. 31%; $p < .001$), and only fair or poor overall health (66% vs. 30%; $p < .001$).

In multivariate analyses adjusting for measures of cardiac function and other patient characteristics, depressive symptoms were strongly associated with greater symptom burden (odds ratio [OR], 1.8; 95% confidence interval [CI] 1.3-2.7; $p = .002$), greater physical limitation (OR, 3.1; 95% CI 2.1-4.6; $p < .001$), worse quality of life (OR, 3.1; 95% CI 2.2-4.6; $p < .001$), and worse overall health (OR, 2.0;
95% CI 1.3-2.9; \( p < .001 \)). Although decreased exercise capacity was associated with worse health status, left ventricular ejection fraction and ischemia were not. This large study provides an interesting perspective on the experience of discomfort, in the form of depressive symptoms, and its apparent influence upon an individual’s physical function, not to mention overall health and quality of life.

Similar results were obtained when Doering, Moser, Lemankiewicz, Luper and Khan (2005) conducted a prospective study involving 72 patients who underwent coronary artery bypass graft surgery (CABG) at an urban, university-affiliated medical center. The purpose of the study was to evaluate emotional and physical recovery from CABG and investigate associations between depressive symptoms and impaired wound healing in patients with high and low depressive symptoms. Baseline measures of functional ability and emotions were taken 48 hours after post-operative extubation and follow-up evaluations were completed at discharge from the hospital and 6 weeks later; medical charts were audited for information regarding post-operative infection. Groups with higher depression scores had lower functional recovery \( (p = 0.009) \) and higher rates of wound complications \( (p = 0.03) \) than those with lower depression scores.

In a cross-sectional prospective study of individuals with the diagnosis moderate to severe COPD entering an outpatient pulmonary rehabilitation program \( (n = 63; 60 \text{ male; 3 female; } M_{age} 65.4 \text{ years; } SD 8 \text{ years}) \), Meek and Lareau (2003) explored relationships among functional performance (measured as
physical activity), functional capacity, symptom experiences, and health-related quality of life. They found there was a significant inverse correlation between perceived efficacy, walking and dyspnea \((r = -0.46, p < .01)\), and fatigue \((r = -0.40, p < .01)\). In addition, there were significant inverse correlations between the 6-minute walk test and dyspnea \((r = -0.40, p < .01)\), and fatigue \((r = -0.36, p < .01)\). Discomforts of dyspnea and fatigue strongly correlated with ability to function. It is logical to conclude that relief of one or both of these uncomfortable symptoms might result in efforts to improve function in terms of perceived and actual performance.

**Summary**

This literature review has addressed the conceptual relationships comprising the study model. There is persuasive evidence to suggest that relationships and comfort influence health-seeking behaviors, both directly and indirectly, within the CCI patient’s experience. Of particular interest is the health-seeking behavior of physical activity as it may contribute to recovery for these challenged patients. The study focused specifically on the CCI patient’s perceptions of relationships during their illness and recovery, their overall comfort experience, and efforts to engage in progressive physical activity as a health-seeking behavior. In doing so, the results of the study advance the current knowledge regarding relationships, comfort, and the health-seeking behavior therapeutic physical activity.
Chapter III

Research Design and Methods

This chapter will present the study’s design, setting, and sample, which were used to answer the research questions. Description of the study design will include its methodology, setting, participant recruitment and enrollment, measures taken to ensure protection of human subjects, and data collection and management. Instrument background and psychometric properties, when available, are described. A description of statistical analyses performed to describe the population sample and answer the research questions are then presented.

Design

The study employed a mixed-method design to describe the associations among relationships, comfort, and therapeutic physical activity in the chronically critically ill (CCI). Previous research was used to develop a conceptual model for the study that suggests how the variables of interest (relationships, comfort, and therapeutic physical activity) are associated in this patient population.

A mixed-method design involves the use of more than one theoretical perspective, methodology, investigator, or data source in a single study (Tashakkori & Teddlie, 2003). By combining one or more of these aspects, a mixed-method research design can increase the ability to interpret the findings (Thurmond, 2001). There were a number of aspects of the study that employed the use of a mixed-method approach. First, two theoretical frameworks, Theory
of Human Relatedness and Theory of Comfort, were used to construct a relevant conceptual framework that guided the study. Second, from a data-source perspective, patient participants provided data regarding states of relatedness, comfort, and participation in therapeutic physical activity while individuals mentioned as contacts by the patient participants provided additional data that allowed an enhanced description of the patients’ social networks. And third, data analyses included descriptive and inferential statistical analyses, as well as social network analysis (SNA). This design was used to answer the following research questions:

1. How do CCI patients describe relationships with family and friends, health professionals, and objects, in terms of states of relatedness and network features, on admission to the LTACH and one month after admission?

2. What is the CCI patient’s level of comfort, on admission to the LTACH and one month after admission?

3. What is the CCI patients’ level of therapeutic physical activity, on admission to the LTACH and one month after admission?

4. What is the association between the CCI patients’ level of comfort and performance of therapeutic physical activity on admission to the LTACH and one month after admission?
5. What are the differences among the CCI patients’ states of relatedness in terms of perceived level of comfort, and performance of therapeutic physical activity?

**Sample, Setting and Protection of Human Subjects**

**Sample.** A convenience sample was recruited from patients who had been newly admitted to the LTACH from an acute care facility following an intensive care unit (ICU) stay of seven or more days. Admission records for the LTACH were reviewed by the research nurse and the medical records of any potential participants were examined to assess eligibility. Medical record information assessment at that time was strictly limited to presence or absence of eligibility criteria.

The initial eligibility criteria were: CCI patients who had been at the LTACH at least 48 hours but no longer than 14 days. After 6 months of recruitment, this criterion was revised to eliminate the 14-day maximum; the rationale for this revision is fully described in Chapter V. Other eligibility criteria were 21 years of age or older; and were able to understand and speak English. Individuals on mechanical ventilation who were assessed as able to consent and participate in the study were considered eligible because the study instruments were amenable to completion with assistance from the researcher, and their perspective was considered unique and valuable.

There were no exclusions based upon gender or ethnicity. Exclusion criteria were: history of severe neurological insult as a result of trauma or stroke;
history of major psychiatric disorder; delirium experienced during or since ICU admission that had not resolved at the time of potential study participation; moderate or severe cognitive impairment, as assessed by the Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1974); or patients deemed inappropriate according to physician judgment related to a medical or neurological condition. These criteria excluded individuals whose mental status prevented them from providing informed consent and/or answering questionnaires, and/or whose condition placed them at end of life, or for whom accurate recall of persons and/or events may have been distorted or not possible (Roberts, Rickard, Rajbhandari, & Reynolds, 2007).

Prior to initiation of recruitment, a random permutation of numbers was computed using the statistical software package SPSS 16.0. This permutation dictated the random assignment of 15 participants to the SNA sub-sample. These participants completed the Social Network Questionnaire (SNQ) and additional Visual Measure of Relatedness tools, in addition to all other study instruments (described in detail later in this chapter). Separate informed consent documents (ICD) were used during recruitment and enrollment to distinguish participants in the primary study from those assigned to the SNA sub-sample (Appendices A & B).

**Setting.** This study was conducted at a 60-bed LTACH located in Northeast Ohio. Within this LTACH, specialized care is provided to patients who require intensive therapies in addition to specialized nursing care due to
their catastrophic illnesses and/or their prolonged dependence on mechanical ventilation. The majority of the patients admitted to this LTACH were from two of the area’s adult acute care hospitals, one with 521 beds (40 beds designated as critical care), the other with 1,235 beds divided among three campuses (44 beds designated as critical care).

**Sample size.** Enrolling a sufficient number of participants is one aspect of research design that can enhance the validity of the findings by reducing the possibility of committing either a Type I or Type II error (Devane, Begley & Clarke, 2004). A Type I error occurs when the researcher incorrectly rejects the Null hypothesis that any detected differences are due to chance alone, thus incorrectly concluding that detected differences were due to the experiment. A Type II error occurs when the researcher incorrectly fails to reject the Null hypothesis, thus incorrectly concluding that detected differences were due to chance alone. Either of these two errors jeopardizes the validity of the findings, which may have implications for the body of knowledge to which the findings would apply.

This study represents early efforts to quantitatively establish correlations among the concepts of relationships, comfort, and therapeutic physical activity in the CCI. Therefore the emphasis was on minimizing the likelihood of a Type II error and an *a priori* calculation to determine a required sample size for significance was deferred. Kolcaba encouraged those using the Comfort Theory to consider setting the desired level of significance, alpha, at 0.1, stating, “When
interventions have few side effects, social scientists (and nurses) incur greater risk of Type II error while protecting aggressively for Type I error” (2003, p. 53). A more stringent alpha, .05 or .01, for example, may prevent the researcher from detecting differences that are clinically significant because they fail to reach statistical significance (a Type II error). Consequently, in this study, the researcher set an alpha of 0.1 to detect statistical significance. Post hoc power analysis, completed using G*power (3rd edition) (Faul, Erdfelder, Lang & Buchner, 2007), supported the significant association between state of relatedness and holistic comfort (1- $\beta$ = 0.96; effect size $r = .641$). The sample size of 24 may not have been sufficient to detect a significant relationship between state of relatedness and therapeutic physical activity (1- $\beta$ = 0.76; effect size $r = .484$). To achieve a power of .80 with an effect size $r$ of .484, a sample size of at least 28 would have been necessary.

**Protection of Human Subjects.** Protection of human subjects was assured by obtaining institutional review board (IRB) approval from University Hospitals Health System and the Frances Payne Bolton School of Nursing, and from the IRB that oversees research conducted in the LTACH. A letter of permission was obtained from the potential participants’ physicians during screening and recruitment. It was anticipated that the primary risk to participants would be loss of privacy; however, the privacy of the study participants was maintained to the highest degree possible.
In the process of collecting network feature data using the Social Network Questionnaire (SNQ), research participants were asked to provide names that correspond to non-object roles identified as “of importance” to him or her. Information collected about those individuals was restricted to name and contact information only, as needed by the researcher for recruitment and enrollment to complete a separate SNQ. Those individuals were considered secondary research participants (Resnik & Sharp, 2006). Secondary research participants were afforded all human research subject protection measures as described in the Common Rule (National Institutes of Health, 2001), including the process of informed consent. Information elicited from secondary participants was restricted to items on the SNQs; they were asked to provide only initials of people identified as important to him or her.

Measures to protect the privacy and confidentiality of the research participants consisted of coding questionnaires and maintaining them separate from the file of participants’ identifying information. Additional measures to protect the privacy of secondary research participants included coding each SNQ-s to correspond only to the primary participant and maintaining the file of secondary participants’ names and contact information separate from their questionnaires.

All study data were stored in a locked, fireproof/waterproof cabinet, and all electronic data were stored in password-protected files. Access to study information was restricted to include only individuals directly related to the
study, including members of the primary researcher’s Dissertation Committee, and the respective IRBs. All results were reported as aggregate findings.

Procedures for conducting research

Recruitment and enrollment. At the beginning of the study, the researcher informed LTACH physicians and nurses of the study protocol and recruiting measures. This was an important step in the recruitment and enrollment process because, by virtue of their relationship with and knowledge of CCI patients, staff nurses were instrumental in providing guidance to the research nurse as to potential participant eligibility (Higgins & Daly, 1999). Potential participants were identified by the nurse researcher from thrice-weekly review of LTACH admission records, and focused review of patient medical records. Nursing staff were then consulted for confirmation of the appropriateness of a potential participant.

For potential participants who were not on mechanical ventilation at the time of screening, the SPMSQ (Appendix C) (Pheiffer, 1974) was administered to provide a baseline assessment of his or her mental status and ability to follow instructions, thus maintaining consistency in study procedures with all participants. The SPMSQ is a 10-item questionnaire that tests orientation, remote and recent memory, and mathematical ability. It is an instrument that allowed the researcher to quickly assess the cognitive status of potential participants. Those who scored more than four errors were considered to have moderate to severe cognitive impairment, and were ineligible to participate in this study.
Recruitment and Enrollment of Participants on Mechanical Ventilation.

For potential participants who were dependent on mechanical ventilation or unable to verbalize due to temporary or permanent intubation (i.e. tracheostomy) the algorithm described by Higgins and Daly (1999) was used for evaluation and consent (See Figure 4). The algorithm served to ensure the important ethical principles of autonomy and justice were maintained within this vulnerable population. Using the algorithm, the researcher identified potential participants from patient admission records on the LTACH units as previously outlined, and then met with the assigned nurse to confirm patient eligibility. The nurse also helped to confirm that the potential participant was considered physiologically stable at the time of consent and of interview. Winkleman, Higgins and Chen (2005) defined physiologic stability as no recent surgery, cardiac, or respiratory emergency or any other event considered compromising the patient’s status in the 24 hours preceding consent and data collection. The rationale for this step was that such an event would be a contraindication for therapeutic physical activity, as defined by this study (Timmerman, 2007), and could temporarily compromise cognitive function (Lim, Alexander, LaFleche, Schnyer & Verfaellie, 2004).

If eligible, the researcher approached the potential participant to briefly describe the study protocol and query the patient’s interest and willingness to participate. If the patient was interested and willing, the researcher confirmed his or her ability to provide informed consent in two steps: first asking the patient to
state his or her name and age (the patient mouthed responses), and then asking the patient to correctly identify the color of paper the researcher held up for him or her. These two steps, according to Higgins and Daly (1999), with correct responses by the patient, demonstrated his or her ability to understand and to follow directions, a vital element to being considered able to provide informed consent. Once these steps had been successfully completed, the researcher reviewed with the patient the full consent document, provided an explanation of the study procedures and obtained either signature or witnessed consent for participation. Any negative response given or indicated, prompted the researcher to consider the patient unable to provide informed consent and efforts to enroll that patient were terminated.
Step 1: Patient meets inclusion criteria?

Yes

No

Stop

Step 2: Patient given brief explanation. Interested?

Yes

No

Stop

Step 3: Patient able to state name and age as requested?

Yes

No

Stop

Step 4: Patient able to identify correct color of paper being held before them?

Yes

No

Stop

Step 5: Further explanation of study and consent document. Willing to consent?

Yes

No

Stop

Step 6: Enroll in study.

Figure 4. Algorithm for consent of a patient receiving mechanical ventilation.

Recruitment and Enrollment of Secondary Participants. Persons identified by research participants completing the SNQ were approached by the principal investigator for recruitment and enrollment into the study as secondary research participants, as defined previously. The researcher recruited only those secondary participants who were at least 21 years of age. During initial contact with a potential secondary participant, the researcher described the study protocol. Potential secondary participants who indicated interest and willingness to participate received an informed consent document and SNQ-s for completion and instructions on how to return them to the researcher. Depending upon the mode of contact with the secondary participant, this was done either by handing the document directly to him or her, mailing it to him or her, or leaving it in a sealed envelope with the patient.

Administration of measures. Once the participant was enrolled, the researcher proceeded with baseline data collection, conducted in the participant’s room so as to maximize his or her comfort within a familiar environment. Measures were taken to secure privacy within this setting (closing doors, or dividing curtains). If the participant was too tired or physically unable to complete the study instruments, the researcher assisted by marking his or her responses on the instruments. In addition, brief rest periods during the interview process were permitted as needed by the participant. The follow-up interview was conducted approximately one month after the initial interview (30 days, +/- 7 days).
Refusals and attrition. Reasons for refusal, when offered by the patient, were collected in order to describe the sample and compare it in terms of those who did consent. Reasons for drop out, if volunteered, were recorded and examined for similarities or patterns in order to better understand attrition in this study, in the chronically critically ill, and for future study design efforts.

Instruments

A schematic of the study timeline and instrument completion specific to each research participant (primary study, SNA sub-sample and secondary participants) can be found in Appendix D. In addition to collection of demographic data (Appendix E), there were four instruments employed in this study to answer the research questions: 1) the investigator-developed Visual Measure of Relatedness (VMR) (Appendices F, G); 2) an investigator-developed tool to identify relationships that participants consider important to them during their present illness and measure the frequency with which the participant has had contact with those persons or objects (SNQ, SNQs; Appendices H, I); 3) the Chronic Critical Illness Comfort Questionnaire (CCICQ) (Appendix J); and 4) the Functional Independence Measure™ (FIM) (State University of New York at Buffalo, 1990) (Appendix K). For the purpose of this study, the distinction between involvement comfort and holistic comfort was maintained when referring to the VMR and CCICQ. Table 1 provides a summary of the study instruments that were used.
Table 1

**Variables and Instruments**

<table>
<thead>
<tr>
<th>Model Category</th>
<th>Variable</th>
<th>Instrument</th>
</tr>
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<tbody>
<tr>
<td>Relationships</td>
<td>1. State of Relatedness</td>
<td>Visual Measure of Relatedness (VMR)</td>
</tr>
<tr>
<td></td>
<td>2. Network Features</td>
<td>Social Network Questionnaire (SNQ, SNQs)</td>
</tr>
<tr>
<td>Comfort</td>
<td>1. Level of Comfort</td>
<td>Chronic Critical Illness Comfort Questionnaire (CCICQ)</td>
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<tr>
<td>Health-seeking</td>
<td>1. Therapeutic physical activity</td>
<td>Functional Independence Measures (FIM)</td>
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<td>Behaviors</td>
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<td>Demographics</td>
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<td>Questionnaire</td>
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<td></td>
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<td>3. race/ethnicity</td>
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<td>4. living arrangement prior to</td>
<td></td>
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<tr>
<td></td>
<td>ICU admission</td>
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<tr>
<td></td>
<td>5. comorbidities upon ICU</td>
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<tr>
<td></td>
<td>admission</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. location at time of interview</td>
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<tr>
<td></td>
<td>7. discharge disposition following</td>
<td></td>
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<tr>
<td></td>
<td>long-term, acute-care hospital stay</td>
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<tr>
<td></td>
<td>8. frequency of participation in</td>
<td></td>
</tr>
<tr>
<td></td>
<td>physical &amp; occupational therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9. route of nutrition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10. wound care measures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11. mechanical ventilation (yes or no)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12. analgesic administration ≤ 1 hour prior to interview (yes or no)</td>
<td></td>
</tr>
</tbody>
</table>

**Relationships**

**Visual Measure of Relatedness.** The two-item Visual Measure of Relatedness (VMR-overall) (see Figure 5) was used to assess the overall state of relatedness for each CCI participant. This visual analog scale (VAS) measured
the participant’s perception of level of overall involvement in his or her relationships, and the sense of comfort derived from that involvement.

Please think about all your relationships, as they are now.

In these relationships would you say, overall, that you are:

X------------------------------------------------------------------------------------------------X*
Not involved at all                                                   Very involved

This amount of involvement makes you feel:

X------------------------------------------------------------------------------------------------X*
Very uncomfortable             Very comfortable

Figure 5. Visual Measure of Relatedness.

The visual analog scale is a straight line, ten centimeters in length, on which the left end of the line represents an absence of the quality in question and the right end of the line represents a high degree of the quality in question (Scott, 2004, p.530). Participants marked the point on the line that corresponded to his or her perception of the quality in question. Based upon Hagerty and colleagues’ conceptualizations (1993), the qualities measured in this study were relationship involvement and resulting involvement comfort. On the VMR, the first item instructed the participant to mark the line according to his or her level, or amount, of overall involvement in his or her relationships. On this line, “no involvement at all” corresponded to zero (0), and “very involved” corresponded to ten (10). The second item instructed the participant to mark the line according
to his or her level of comfort associated with the level of involvement, where “very uncomfortable” corresponded to zero (0), and “very comfortable” corresponded to ten (10).

The participants selected for the SNA sub-sample completed a VMR-specific for each relationship listed on his or her SNQ. The VMR-specific assessed the qualities of involvement and involvement comfort regarding specific relationships using questions similar to the VMR-overall.

Using the values of the responses for the two questions, a state of relatedness was plotted on an x-y coordinate diagram for each participant, and for each relationship reported by participants in the sub-sample. The methodology is explained further in the discussion of the analysis of research question one.

The criterion-related validity of a VAS to measure symptoms and mood has been reported in the literature (Scott, 2004; McGuire, Kim & Lang, 2004; Ahearn, 1997). As a measurement instrument, the VAS is useful when the object of measurement is abstract and not easily quantified (Gould, Kelly, Goldstone & Gammon, 2001). Harries, Booker, Rehaln & Collins’ (1983) study of relationships among standardized walking tests, lung function, and a VAS of breathlessness found a significant correlation between the standardized walking tests and the VAS \( r = 0.7, \ p < 0.00001 \) in patients with emphysema. In the late 1960’s, Zealley and Aitken were among the first to establish the validity of a self-rated VAS as a measure of mood (Ahearn, 1997). In their study they found a high correlation
between patients’ self-reported VAS of mood and their score on the Hamilton Depression Scale score, a standardized measure of mood ($r = .78$, $p < .001$). The retest reliability of the VAS has also been documented. In Ahearn and Carroll’s study of unipolar and bipolar depressed patients (1996), they evaluated the short-term (30 minutes) reliability of the Mood Visual Analogue Scale (MVAS). The correlation coefficient ratings were 0.82 and 0.89, respectively, indicating acceptable retest reliability for those patients.

**Network Features.** Participants in the sub-sample were asked to identify as many as seven relationships of importance to them during their present illness. The participant was asked to indicate how each person or object of importance is known by the participant and describe how frequently he or she interacts with the relationship partner. Each person identified by the CCI participant was recruited to complete identical questions about relationships of importance, including the CCI participant, and how frequently they interact with those persons or objects.

The importance of assessing multiple types of relationships (personal, professional, or object-based) is supported in a study by LaGuardia, Ryan, Couchman, and Deci (2000). In a multi-phased study of more than 300 undergraduate students, they found that satisfaction of inherent needs for relatedness, autonomy, and competence, with respect to a wide range of relationships, predicted attachment security and perceptions of well-being within those relationships ($r = .65$, $p < .001$, $r = .48$, $p < .001$, respectively).
Holistic Comfort

**Chronic Critical Illness Comfort Questionnaire.** Kolcaba’s primary assertion regarding the concept of comfort is that patients (and families) frequently want, and need, to be comforted in times of illness (2003). The GCQ was developed from Kolcaba’s early work on the Theory of Comfort (1992) as a means of operationalizing the concept of holistic comfort. The General Comfort Questionnaire (GCQ) (Kolcaba, 1992) and adaptation, the Hospice/End of Life Comfort Questionnaire (EOLCQ) (Novak, Kolcaba, Steiner & Dowd, 2001), were two measures of holistic comfort designed to assess this concept in different patient settings. The internal consistency of the original GCQ’s 48 items was reflected in a Cronbach’s alpha of 0.88; individual subscales, which represent the comfort contexts of physical, psychospiritual, environment, and social, yielded Cronbach’s alphas of 0.66 to 0.80.

In 2001, Novak, Kolcaba, Steiner and Dowd conducted a two-phase study that recruited hospice patients (n = 38) and their caregivers (n = 48) to assess two measures of comfort at end-of-life. The EOLCQ was one of these measures, adapted from Kolcaba’s GCQ (Kolcaba, 1992). It contained the same number of items, with some reworded to address end-of-life issues such as comfort related to one’s life as a whole, the decision to enter hospice, and fear of the unknown. In addition, there were two versions of the EOLCQ, one for patients and one for caregivers. In the second phase of the study the EOLCQ demonstrated high internal consistency, with Cronbach’s alphas of .83 for patients and .89 for...
caregivers, indicating an acceptable reliability for adaptation as a measure of comfort in the CCI.

The Chronic Critical Illness Comfort Questionnaire (CCICQ) was adapted by the researcher from the EOLCQ (Novak, Kolcaba, Steiner & Dowd, 2001). Three items from the EOLCQ that addressed issues surrounding the hospice experience and/or imminent death were removed. An additional item was created, “I feel safe here”, to correspond with literature that suggests safety is a psychological need considered important to critically ill patients (Hupcey, 2000), yielding a 46-item tool. The revised questionnaire consisted of 46 positively and negatively worded items that operationalized the concept of comfort as outlined by Kolcaba (1992). Scoring was completed by reversing negatively worded items and adding the total. Subscale scores were calculated to represent the contexts of physical, psychospiritual, environmental, and social comfort. The possible range of the total score is 46-184; subscale scores range from 12-48 for the physical context, 14-56 for the psychospiritual context, 10-40 for the environment context, and 10-40 for the social context. Higher scores indicate higher levels of holistic comfort. For the purposes of this study, the total score from the CCICQ was used in data analyses.

Health-seeking Behavior/Therapeutic Physical Activity

Functional Independence Measure. The Functional Independence Measure™ (FIM) is an 18-item instrument that measures the level of independence a person exhibits in personal activities of daily living (self-care,
sphincter control, transfers, and locomotion) as well as communication and cognition (Chiang, Wang, Wu, Wu & Wu, 2006). There were four scores generated: a FIM-total (all 18 items), and the subscale scores for self-care, transfers and locomotion (Houlden, Edwards, McNeil & Greenwood, 2006). Items were scored 1 (total assistance required) to 7 (complete independence). Total scores range from 18 (lowest possible function) to 126 (highest level of function). The FIM is an integral component of the Uniform Data System for Medical Rehabilitation (UDS), widely used as a benchmark for comparison of rehabilitation programs and for accreditation purposes (Dodds, Martin, Stolov & Deyo, 1993).

Psychometric properties of the FIM for diverse rehabilitation patients were reported by Dodds and colleagues (1993). They analyzed the data on more than 11,000 general rehabilitation patients in the Pacific Northwest (Mage 65, 17% < 45 years, 21% 45-65 years, 29% 65-75 years, 33% > 75 years; 51% male). Their sample included patients with diagnoses of stroke (52%), orthopedic conditions (10%), and brain injury (10%). Like the CCI population, 93% of the patients were living in their own homes prior to episodes that resulted in a need for rehabilitative treatment.

The FIM demonstrated high internal consistency with Cronbach’s alpha (admission FIM-total = 0.93, discharge FIM-total = 0.95). The authors tested the FIM’s responsiveness by using a paired t-test to assess change over time. The FIM detected significant clinical improvements from admission to discharge for
all patients (33% average FIM score improvement, \( p < .0005 \)) and across all diagnostic groups (\( p < .0005 \)). Finally, they examined construct validity by considering whether FIM scores varied according to age and discharge destination (reflecting the amount of functional independence achieved). Correlations that fit an expected pattern, such as those for discharge age, co-morbidities, and discharge destination, contribute evidence of construct validity. There were differences among scores across diagnostic groups according to age and co-morbidities, as expected, although they did not reach statistical significance. The differences in discharge destination were strongly associated with differences in FIM scores (\( p < .000 \)). Thus, these findings support the construct validity of the FIM by demonstrating clinical correlation with age and co-morbidities, and a statistically significant correlation with discharge destination.

Houlden, Edwards, McNeil, and Greenwood (2006) recently compared the appropriateness and responsiveness of the FIM to the Barthel, another frequently-used measure of functional ability, during early inpatient rehabilitation after single-incident brain injury. Their sample was comprised of 152 patients with vascular brain injury (\( M_{\text{age}} 47.7 \) years, SD 10.4 years; 58% male) and 107 patients with traumatic brain injury (\( M_{\text{age}} 37.5 \) years, SD 13.4 years, 87% male) who were hospitalized a minimum 7 days. Appropriateness was defined by the authors as “whether the range of problems in a study sample can be effectively gauged by a measuring system or tool” (p.155). Floor and ceiling
effects, percentages of the study population at the lowest and highest possible scores, respectively, were calculated as indicators of appropriateness. The floor and ceiling effects for the Barthel Index (5.2 and 11.3%, respectively) were greater than those for the FIM scores (0% and 6.5%, respectively). The authors defined responsiveness as “the ability of a measure to detect clinically important change” (p. 155), and calculated effect size ($M_{\text{change score}} / \text{SD of admission scores}$) as an indicator. The effect size for vascular brain injury using the FIM was 0.59, the Barthel, 0.65; for traumatic brain injury, the FIM registered an effect size of 0.52, the Barthel, 0.55. Thus the FIM remains an appropriate and responsive measure of functional ability and improvement within the rehabilitation setting; the relatively low floor and ceiling effects make it particularly sensitive to a wide range of functional levels.

According to the LTACH protocol, each patient is evaluated according to FIM items by a licensed physical therapist (PT) once per week (personal communication). This information becomes part of the patient’s medical record documentation for ongoing comparison of physical progress. Prior to initiation of this study, the researcher was trained to administer the FIM by the LTACH Physical Therapy staff. During the study, the researcher administered the FIM to all study participants at baseline and follow-up. The researcher-generated FIM scores (total) were used for data analysis. The FIM scores recorded in participants’ medical records as completed within 24 hours of the researcher’s measurement, when available, were used to calculate inter-rater reliability.
**Data obtained from the medical record.** Demographic data obtained from the participant’s medical record consisted of: age, gender, race/ethnicity, comorbidities upon admission to ICU, living arrangements prior to admission to the ICU, location at the time of the interview, discharge disposition following LTACH, frequency of participation in physical and occupational therapy, route of nutrition, wound care measures, whether or not the participant is on mechanical ventilation (MV) at the time of the interview, FIM score (total), and analgesic agent administration ≤ 1 hour prior to the interview.

**Data Analyses**

Descriptive statistics (frequencies, percentages) and measures of central tendency were used to describe the study sample with regard to the demographic variables, holistic comfort, and functional ability.

**Social Network Analysis.** A sociogram for each SNA sub-sample participant was created using data from his or her SNQ and SNQs’. These questionnaires identified participants’ important relationships and the frequency of contact with those persons or objects. A sociogram is a graphical depiction of a social network. In this study, sociograms were used to explore and describe the different roles and dynamics that relationships assume during chronic critical illness.

An innovative approach to describing and understanding relationships, SNA is a methodology that is often used to study organizations and organizational behavior in terms of social structure (Marsden, 1990; Scott, et al,
It combines the visual representation of relationships within a designated group (sociogram) with analysis of interaction patterns to yield quantitative comparisons of relationship structure and function (Scott, et al, 2005). The use of SNA in healthcare has been largely at the organizational level (Scott, et al, 2005), for example, to study physician practices in order to make recommendations that improve efficiency and productivity. Recently, Lurie and colleagues used SNA to describe clinical team functioning in an ICU, interdisciplinary collaboration between clinical and academic departments at the organizational level (2009). There is no known research that used SNA to quantify and describe individual CCI patients’ relationships; however, it was anticipated that SNA can be useful at the clinical level to understand network features such as how often the CCI patient is in contact with persons or objects of importance to him or her during the illness.

There were two aspects of SNA of interest for the study: degree centrality and betweenness centrality. Centrality can be understood as importance (italics added) (Bader, Kintali, Madduri & Mihail, 2007). Degree centrality is described as the number of direct connections an individual has to other individuals, or, the importance of one individual in linking others to the social network. Betweenness centrality refers to how an individual’s direct connections may position them to access other indirect connections (Krebs, 2008). This aspect of centrality speaks to who controls the flow of information and resources within the network (Knoke & Yang, 2008). The software program Pajek reports these
two types of centrality. When used to describe the relationships of CCI patients, these two aspects of SNA will provide a better understanding of the dynamics of their connections and suggest how network features may influence their comfort and therapeutic physical activity.

For the purposes of this study, SNA data were patient participant responses to the questions 1) Please identify at least seven relationships of importance to you during your present illness, 2) What is this person/object’s relationship to you, and 3) How often [not at all/not often/somewhat often/very often], in the past few days, have you had contact with [name of each person and/or object identified from the first question]? Persons identified by patient participants’ SNA responses were then queried using an adapted tool containing similarly worded questions. This information was collected at baseline and follow-up. The data were analyzed to answer the research questions using Pajek®, a software program that allows analysis and graphical representation of social networks.

**Research Questions.** Research question 1 (How do CCI patients describe relationships with family and friends, health professionals, and technology supports, in terms of states of relatedness and network features, on admission to the LTACH and one month after admission?) were answered by graphical analyses of the scores of the two items of the Visual Measure of Relatedness, as perceived by participants. Using a computer software program designed for graphical computations and visualization of data, the scores of the responses for
the two questions were plotted on an x-y coordinate diagram for each participant (see Figure 6).

![Diagram of states of relatedness]

**Very Involved**

<table>
<thead>
<tr>
<th>Enmeshment</th>
<th>Connectedness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very uncomfortable</td>
<td>Very comfortable</td>
</tr>
<tr>
<td><strong>Disconnectedness</strong></td>
<td><strong>Parallelism</strong></td>
</tr>
<tr>
<td>Not at all involved</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 6. States of Relatedness*; x-axis = level of comfort, y-axis = degree of involvement.

Note: The lines of measurement were arranged such that involvement is the Y-axis and comfort is the X-axis, crossing one another at their respective mid-points (five centimeters).


The plotted scores of the Visual Measure of Relatedness indicate the participant’s state of relatedness based on the combined scores of ‘level of involvement’ and ‘level of comfort with involvement’: connectedness, characterized by a high level of involvement and high level of comfort with involvement; parallelism, characterized by a low level of involvement and high level of comfort with involvement; disconnectedness, characterized by a low level of involvement and discomfort; and enmeshment, characterized by a high level of involvement and discomfort with this level of involvement. Descriptive
statistics (percentages) were used to categorize the study sample in terms of overall states of relatedness.

Research questions 2 (What is the CCI patients’ level of holistic comfort, upon admission to the LTACH and one month later?) and 3 (What is the CCI patients’ level of therapeutic physical activity, on admission to the LTACH and one month after admission?) were answered using paired t-tests. Because holistic comfort and therapeutic physical activity were measured as continuous variables, the paired t-test was an appropriate statistical test to compare participant’s mean scores on the CCICQ and the FIM across the two time points of baseline and one month after admission (Polit & Beck, 2004).

Research question 4 (What is the association between the CCI patients’ level of comfort and performance of therapeutic physical activity on admission to the LTACH and one month after admission?) were answered using Pearson’s product moment calculations for each time point. The Pearson’s product moment correlation calculation is an appropriate test to assess the magnitude and direction of association between the two continuous variables of holistic comfort and therapeutic physical activity as measured by the CCICQ and FIM, respectively (Polit & Beck, 2004).

Research question 5 (What are the differences among the CCI patients’ states of relatedness in terms of perceived level of comfort, and performance of therapeutic physical activity?) were answered using one-way analysis-of-variances (ANOVA). Because the four states of relatedness (overall) were coded
as categories, while holistic comfort and therapeutic physical activity were continuous measures, ANOVA is an appropriate statistical test to compare the means among two or more categories (Munro, 2005). Specifically, the differences among states of relatedness and level of comfort, as measured by the CCICQ were explored, as will differences among states of relatedness and therapeutic physical activity, as measured by the FIM.

**Pilot Study**

A pilot study was conducted using baseline data collected in order to evaluate the protocol, data collection instruments, recruitment strategies, and data management. Results of this study were used to make any necessary adjustments to the design or implementation of the protocol.

**Summary**

In this chapter, the author has described the study design, instruments, data analysis, and measures to protect human subjects. It is expected that the results of this study represent important contributions to the body of knowledge about the care and outcomes of the CCI and will stimulate further research for innovative and effective nursing interventions.
Chapter IV

Results

The purpose of this study was to expand our knowledge of the role relationships play during chronic critical illness by investigating chronically critically ill (CCI) patients’ perceptions of their relationships, and the associations among their relationships and states of relatedness, comfort, and therapeutic physical activity. Figure 7 illustrates the conceptual model used to guide the study. Data were collected while participants were admitted to a long-term care hospital and one month after enrollment.

![Figure 7. Conceptual Framework/Study Model](image)

This chapter provides a description of the study sample, followed by findings specific to the research questions.

The research questions were:

1. How do Chronically Critically Ill (CCI) patients describe relationships with family and friends, health professionals, and objects, in terms of
states of relatedness and network features, on admission to the Long Term Acute Care Hospital (LTACH) and one month after admission?

2. What is the CCI patient’s level of comfort, on admission to the LTACH and one month after admission?

3. What is the CCI patients’ level of therapeutic physical activity, on admission to the LTACH and one month after admission?

4. What is the association between the CCI patients’ level of comfort and performance of therapeutic physical activity on admission to the LTACH and one month after admission?

5. What are the differences among the CCI patients’ states of relatedness in terms of perceived level of comfort, and performance of therapeutic physical activity?

Description of the sample

Setting and Sample

Potential participants were selected from two 21-bed units in a Long Term Acute Care Hospital located in Northeast Ohio. Screening and enrollment occurred between September, 2009 and January, 2011. Figure 8 displays the sample selection process. Two-hundred eighty-three patients were screened for eligibility. More than 50% of screened patients were ineligible because of neurocognitive dysfunction. Nineteen patients declined participation, with the predominant reason given as fatigue (n=11), a factor that is consistent with other CCI-based studies reported in the literature (Daly, et al., 2005). Thus 32 patients
were enrolled; 24 participants completed baseline and follow-up measures and comprised the final sample for analysis. The attrition rate of 25% also is consistent with the literature for this patient population (Nasraway, Button, Rand, Jinks & Gustafson, 2000; Daly, et al., 2005). Six of the 24 participants, who were randomly selected, completed Social Network Analysis (SNA).
Figure 8. Sample Selection
Sample Description. Table 2 displays the demographics of the sample. Participants’ mean age was 64.8 years (range 31-84); the sample was predominantly female (58.3%) and Caucasian (95.8%). A majority of participants had either respiratory or cardiac dysfunction upon admission to the acute care facility ICU (37.5%, 33.3%, respectively). The attrition rate for this sample was 20%, which is similar to that in other CCI-focused studies (Douglas, Daly, Brennan, Harris, Nochomovitz & Dyer, 1997; Douglas, Daly, Gordon & Brennan, 2002). The 24 participants who completed all measures were not statistically different from the 8 participants who did not complete follow-up measures with regard to age, gender, reason for ICU admission or discharge disposition. The six participants who completed network analysis measures did not differ significantly from the rest of the sample with regards to these variables, except race; all were Caucasian.

Although 87.5% of participants lived at home prior to ICU admission, just 29.2% were discharged home or to an assisted living environment; 70.8% were discharged to another health-care facility for either long-term nursing care or rehabilitation. Seventy-one percent of participants were admitted to the LTACH for ongoing aggressive respiratory management, including weaning from mechanical ventilation (n=2). Other measures of chronic critical illness revealed that 25.1% of participants were being treated for extensive wounds with use of either a continuous wound-vac appliance or debridement measures, 58.3% of participants took nutrition orally, and 54.2% of participants were active in
physical therapy 5 times per week. Co-morbidity profiles indicated that 54.2% of
the study sample had heart disease, 45.8% had a pre-existing respiratory
disorder, 41.7% had hypertension, and 33.3% were diabetic. Other co-morbidities
reported were morbid obesity (20.8%), and renal dysfunction (12.5%).
Table 2

**Demographics of the Sample (n = 24)**

<table>
<thead>
<tr>
<th></th>
<th>M (range; SD)</th>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>64.8 yrs (31-84; 13.7 yrs)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>14 (58.3)</td>
</tr>
<tr>
<td>Male</td>
<td>10 (41.7)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>23 (95.8)</td>
</tr>
<tr>
<td>African-American</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td><strong>Reason for ICU admission</strong></td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td>8 (33.3)</td>
</tr>
<tr>
<td>Respiratory</td>
<td>9 (37.54)</td>
</tr>
<tr>
<td>Surgical/Trauma</td>
<td>6 (24.5)</td>
</tr>
<tr>
<td>Sepsis/Other</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td><strong>Discharge disposition</strong></td>
<td></td>
</tr>
<tr>
<td>Other health-care facility</td>
<td>17 (70.8)</td>
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<tr>
<td>Home or Assisted living</td>
<td>7 (29.2)</td>
</tr>
</tbody>
</table>

The mean length of LTACH stay-to-baseline measurement was 11.4 days (3-49; SD 9.4 days). In this observational study, the interval between time 1 (baseline) and time 2 (follow-up) data collection was dictated by patient care
needs. Clinical routines, interim readmission to an acute care facility before returning to the LTACH, and patient stability are three examples of circumstances that influenced the length between data collection periods. The mean length of follow-up interval was 42.4 days (range 14-156; SD 31.1 days). Cases with baseline and follow-up data (n = 24) were analyzed and are presented in the following sections. Six of the 24 participants provided network analysis information.

**Results**

**Research Question 1**

The research question, “How do CCI patients describe relationships with family and friends, health professionals, and objects, in terms of states of relatedness and network features, on admission to the LTACH and one month after admission?” was answered using data from the Overall Visual Measure of Relatedness (VMR) and the Social Network Questionnaire (SNQ).

**Overall States of Relatedness**

All participants (n = 24) completed the VMR, a two-item visual analog scale (VAS) that measures each participant’s perception of level of involvement in his or her relationships (0-10), and sense of comfort derived from that involvement (0-10). An overall state of relatedness for each participant was plotted on the x-y coordinate diagram. Level of involvement scores are plotted on the y-axis, involvement-derived comfort scores are plotted on the x-axis. Figure 9 represents participants’ states of relatedness at baseline and follow-up
within the context of Hagerty and colleague’s model (Hagerty, Lynch-Sauer, Patusky, and Bouwsema, 1993).

Participants who reported levels of involvement and involvement-derived comfort greater than 5.0 are categorized as Connected; those who reported levels of involvement greater than 5.0 with involvement-derived comfort of 5.0 or less are categorized as Enmeshed. Participants who reported levels of involvement and involvement-derived comfort of 5.0 or less are Disconnected, while those who reported levels of involvement of 5.0 or less with involvement-derived comfort greater than 5.0 are categorized as Parallel. Table 3 shows the overall states of relatedness scores at baseline and follow-up.

Table 3

*Overall States of Relatedness – Baseline & Follow-up (n = 24)*

<table>
<thead>
<tr>
<th>State</th>
<th>Baseline n (%)</th>
<th>Follow-up n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connectedness</td>
<td>17 (70.8)</td>
<td>15 (62.5)</td>
</tr>
<tr>
<td>Parallelism</td>
<td>3 (12.5)</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Enmeshment</td>
<td>1 (4.2)</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>Disconnectedness</td>
<td>3 (12.5)</td>
<td>7 (29.2)</td>
</tr>
</tbody>
</table>

A closer look at the 24 participants’ overall scores states indicated 14 did not change from baseline to follow-up: 11 were connected, 1 was enmeshed, 2 were disconnected. Five participants went from connected to disconnected, 3
went from parallel to connected, 1 participant went from connected to parallel, and 1 went from disconnected to connected. Figure 9 shows the graphical depiction of the plotted scores.
Figure 9. Overall States of Relatedness (n=24) – Baseline & Follow-up

Note: Numbers corresponding to symbols indicate participant’s study code number.
* 8 participants had these coordinates at baseline, 6 at follow-up.

Social Network Analysis

Social network analysis sub-study

To describe network features, SNA participants (n=6) completed the SNQ, identifying as many as seven relationships of importance during their present illness. The participants indicated whether each person or object of importance was a relative, friend or acquaintance, health care professional or
object; the participants also indicated how frequently he or she interacted with the relationship partner in the preceding three days. Subsequently, each person identified by the network analysis participant was recruited as a Secondary Participant and asked to complete an SNQ, indicating as many as five relationships and frequency of contact with those relationships, beginning with the CCI patient. Each network analysis participant also completed the VMR for each relationship identified on the Social Network Questionnaire.

**Network Features**

Network features are described using the SNA sample data from the Overall VMR, the Social Network Questionnaires and the VMR-specific for each reported relationship. The six network analysis participants who completed baseline and follow-up measures identified a total of 29 relationships of importance at baseline and 27 at follow-up. Analysis revealed no significant associations between the participant’s state of relatedness score and type of relationship, or frequency of contact at baseline. But on follow-up, the association between state of relatedness and frequency of contact was statistically significant, according to a Pearson contingency coefficient ($P = 0.624, p < .01$).

**States of Relatedness.** At baseline, network analysis participants characterized the overall states of connectedness, parallelism, and disconnectedness equally, with two in each state (33.3% per state). At follow-up, four participants reported a sense of connectedness (66.7%), while one participant indicated a state of disconnectedness (16.7%) and one indicated a
state of parallelism (16.7%). Specific states for these relationships were predominantly connected (75.9%), with the remainder parallel (24.1%) at baseline; at follow-up, participants characterized the specific relationships as connected (81.5%), parallel (11.1), or enmeshed (7.4). Figure 10 depicts participants’ overall states of relatedness at baseline and follow-up.

Figure 10. Overall States of Relatedness of SNA Sample –Baseline & Follow-up (n = 6)

Note: Numbers corresponding to symbols indicate participant’s study code number.

**Types of relationships and frequency of contact – Social Network**

**Analysis.** Figure 11 is a configuration of the CCI patient’s social network at
baseline. The outlying circles represent the different types and relative proportions of important relationships that SNA participants identified. Of these relationships, 22 (75.9%) were relatives (spouse, sibling), 3 (10.3%) were friends or acquaintances, 3 (10.3%) were health care providers (speech therapist, occupational therapist, nursing technician), and 1 (3.4%) was an object (nature). The proportions were similar at follow-up (see Table 4).

The mix of relationships within networks was varied at baseline. Each of the six participants named at least one family member as an important relationship; two named at least one friend as an important relationship; one participant named health care providers among important relationships, while another named an object (nature). At follow-up, three of the six participants’ networks included only family members; two included friends, and one included a health care professional and an object.
Figure 11. The CCI Patients’ Social Network – Relationships of Importance* - Baseline

Note. * - participant-reported; HCPs – health care providers; Obj – objects.
Table 4

*SNA Participants’ Important Relationships - Type of Relationship & Frequency of Contact*

<table>
<thead>
<tr>
<th>Type of Relationship</th>
<th>Baseline n = 29</th>
<th>Follow-up n = 27</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Relative</td>
<td>22 (75.9)</td>
<td>21 (77.8)</td>
</tr>
<tr>
<td>Friend/Acquaintance</td>
<td>3 (10.3)</td>
<td>4 (14.8)</td>
</tr>
<tr>
<td>Health Care Professional</td>
<td>3 (10.3)</td>
<td>1 (3.7)</td>
</tr>
<tr>
<td>Object</td>
<td>1 (3.4)</td>
<td>1 (3.7)</td>
</tr>
</tbody>
</table>

Frequency

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Baseline n = 29</th>
<th>Follow-up n = 27</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Very Often</td>
<td>17 (58.6)</td>
<td>8 (29.6)</td>
</tr>
<tr>
<td>Somewhat Often</td>
<td>11 (37.9)</td>
<td>16 (59.3)</td>
</tr>
<tr>
<td>Not Often</td>
<td>1 (3.4)</td>
<td>2 (7.4)</td>
</tr>
<tr>
<td>Not at All</td>
<td></td>
<td>1 (3.7)</td>
</tr>
</tbody>
</table>

**Exemplar cases – states of relatedness and network features.** The data from two network analysis participants regarding states of relatedness and network features are presented here to further illustrate the different roles and dynamics that relationships assume during chronic critical illness. Participant #1 indicated an overall Parallel state of relatedness and identified five relationships of importance: two relationships were Connected (spouse, son) and three were
Parallel (siblings). Participant #2 also indicated an overall Parallel state of relatedness and identified seven relationships of importance: five relationships were Connected (spouse, sisters, a religious organization, and a nurse) and two were Parallel (occupational therapist, speech therapist).

Network features are illustrated using sociograms (see Figures 12 and 13) derived from the two participants’ Social Network Questionnaires and his or her secondary participants’ Social Network Questionnaires. CCI and secondary participants were asked to identify relationships of importance to him or her at the time of interview; secondary participants were further advised that relationships of importance would be those which involved patient care. Then participants were asked to indicate how often he or she had had contact with each person identified. Pajek©, a social network analysis software program, was used to create the sociograms, which are visual representations of the CCI patient’s relationships and frequency of contacts. The arrows indicate the direction of the relationship, as informed by patient and secondary participants who completed Social Network Questionnaires (i.e., not all potential secondary participants responded). The width of connecting lines (vectors) represents the participants’ perception of frequency of contact with that individual. The thickest line represents contact that was “very often”, while the thinnest line depicts contact perceived as “not often”. Lines of medium thickness depict contact perceived as “somewhat often”. The remaining four network analysis participants’ baseline sociograms can be viewed in Appendix O.
Figure 12. SNA Participant #1 – Social Network at Baseline (includes secondary participant data*)

* secondary participants responding were Spouse, Brother 1, and Sister.
Figure 13. SNA Participant #2 – Social Network at Baseline (includes secondary participant data*)

Note. * secondary participants responding were Occupational therapist and Speech therapist.

**Data collection limitations.** Thirty percent of potential secondary participants responded to the researcher’s attempts to establish contact for recruitment. Individuals with whom the researcher spoke but who declined to participate described being overwhelmed with the CCI patient’s illness and added responsibilities since their loved one fell ill, as well as reluctance to divulge what was considered private information as reasons for declining. In Wiencek’s unpublished dissertation (2008), she reported a CCI proxy response
rate of 28.2%, comparable to this study. Because of this low response rate from potential secondary participants, the social network sociograms are not fully representative of the CCI patients’ networks. However, the sociograms do shed light on the nature of relationships considered most important to CCI patients in that they are predominantly family members, and that the frequency of contact with these individuals is “very often” or “somewhat often”.

Research Question 2

The Chronic Critical Illness Comfort Questionnaire

Participants responded to the 46-item Chronic Critical Illness Comfort Questionnaire (CCICQ), providing data that answered the question, “What is the CCI patient’s holistic level of comfort, on admission to the LTACH and one month after admission”. The researcher adapted this measure from Novak and colleagues’ End of Life Comfort Questionnaire (EOLCQ; Novak, Kolcaba, Steiner & Dowd, 2001), a revision of Kolcaba’s General Comfort Questionnaire (GCQ; 1992). Adaptation consisted of removing three items from the EOLCQ that pertained specifically to impending death. One item was inserted to evaluate participants’ perception of personal safety in the LTACH, a concept that Hupcey (2000) reported as an important psychological need of critically ill patients.

The Comfort Questionnaire consists of 46 positively and negatively worded items that operationalize the concept of holistic comfort; a participant responded as to whether he or she strongly disagreed, disagreed, agreed or strongly agreed with each item. Scoring was completed by reversing negatively
worded items and calculating a total. The four subscales represent the contexts of physical, psychospiritual, environmental, and social comfort. The possible range of the total score is 46-184; subscale scores can range from 12-48 for the physical context, 14-56 for the psychospiritual context, 10-40 for the environment context, and 10-40 for the social context. Examples of items that measured physical comfort are, “I am at ease physically” and, “My pain is difficult to endure”. Items that measured psycho-spiritual comfort included, “I feel guilty” and, “I have found meaning in my life”. Social comfort was measured with items such as, “No one understands me” and, “I need to be better informed about my condition”. Comfort in the context of a participant’s environment was measured with items such as, “I feel safe here”, and, “The mood around here is depressing”. Higher scores indicate higher levels of holistic comfort.

In a previous study with cardiac patients (Kolcaba, 1992), the General Comfort Questionnaire demonstrated a Cronbach’s alpha of 0.88 for total scores; individual subscales yielded Cronbach’s alphas of 0.66 to 0.80. In Novak and colleagues’ study of hospice patients and their caregivers (2001), the End Of Life Comfort Questionnaire total demonstrated a Cronbach’s alpha of 0.83 for patients and 0.89 for caregivers.

In this study, the CCICQ demonstrated a Cronbach’s alpha of 0.87, suggesting acceptable internal consistency and favorable comparison to the General and the End Of Life Comfort Questionnaires. The internal consistency of the subscales was comparable to those of the General Comfort Questionnaire.
Subscale Cronbach’s alpha results for this study ranged from 0.885 for the psychospiritual subscale to 0.614 for the social subscale. Correlation of the Visual Measure of Relatedness Overall and Social Subscale of the CCICQ (as a measure of validity for the VMR) was -0.372, an inverse correlation that is congruent with the premise that disconnectedness is associated with lower overall social comfort.

**Holistic comfort in the CCI**

Table 5 shows the scores for total comfort among the participants, as well as the subscale scores at baseline and follow-up; paired-samples $t$-tests were conducted to determine whether changes in the scores over time were statistically significant. At baseline, participants indicated a moderate amount of total comfort, with a mean score of 133.21 (range 92-167, SD 16.08); total comfort increased over time, with a mean follow-up score of 139.33 (range 103-165, SD 17.45). The difference in total comfort over time was not significant ($t = -1.89$, $p = 0.071$).
Table 5

*Holistic Comfort in the CCI at Baseline & Follow-up (n = 24)*

<table>
<thead>
<tr>
<th>CCICQ Component</th>
<th>Baseline (M (range, SD))</th>
<th>Follow-up (M (range, SD))</th>
<th>t (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (46-184)</td>
<td>133.21 (92-167, 16.08)</td>
<td>139.33 (103-165, 17.45)</td>
<td>-1.89 (.071)</td>
</tr>
<tr>
<td>Subscales</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical (12-48)</td>
<td>31.08 (23-40, 4.66)</td>
<td>34.12 (24-43, 5.19)</td>
<td>-2.97 (.007)*</td>
</tr>
<tr>
<td>Psycho-spiritual (14-56)</td>
<td>41.46 (20-56, 8.29)</td>
<td>43.17 (26-53, 7.30)</td>
<td>-1.48 (.153)</td>
</tr>
<tr>
<td>Environmental (10-40)</td>
<td>30.42 (19-38, 4.37)</td>
<td>31.83 (19-39, 5.15)</td>
<td>-1.12 (.274)</td>
</tr>
<tr>
<td>Social (10-40)</td>
<td>29.83 (21-38, 4.26)</td>
<td>30.21 (23-37, 3.89)</td>
<td>-0.44 (.667)</td>
</tr>
</tbody>
</table>

*Note.* *p* < .01.

Examination of the baseline subscale scores suggests that comfort in the physical context was the lowest with regard to possible score, with the mean of 31.08 (range 23-40, SD 4.65); CCI patients’ comfort in the environmental context was highest with regard to possible score, with a mean of 30.42 (range 19-38, SD 4.37). At follow-up, all subscale scores increased, but only the increase in the physical context subscale score was statistically significant (*t* - 2.97, *p* < .01).

**The Chronically Critically Ill - Variables of holistic comfort**

The researcher examined responses for individual items of the Comfort Questionnaire to gain an appreciation for the unique comfort needs of the
chronically critically ill. Table 6 presents a sample of items for which 75% or more of the sample responded “agree”’ or “strongly agree”. Other items predominantly agreed upon by respondents are mentioned in the following paragraphs.

**Comfort in the Psycho-spiritual Context.** CCI participants indicated a strong sense of spirituality, as 86.7% of participants at baseline agreed or strongly agreed with the statement “I feel confident spiritually”, and 80.7% of participants at baseline agreed or strongly agreed with the statement “My God is helping me”. Further, 77.4% of participants at baseline agreed or strongly agreed with the statement “I feel peaceful”.

**Comfort in the Social Context.** When it came to comfort within the context of interpersonal relationships, those with family and friends, as well as those with healthcare providers, 93.5% of participants at baseline agreed or strongly agreed with the statement, “I am ok with my personal relationships”. There was also a perception of bonds with friends as 80.6% of participants at baseline agreed or strongly agreed with the statement, “My friends remember me with cards and phone calls”. Lastly, 80.4% agreed or strongly agreed with the statement, “There are those I can depend upon when I need help.”

Table 6

**CCICQ Items of Interest in the Chronically Critically Ill**

<table>
<thead>
<tr>
<th>Comfort Item</th>
<th>Agree/Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Physical Context

I feel good enough to do some things for myself 94.6%
I have difficulty resting 83.9%
I can rise above my pain 83.8%

Psycho-spiritual Context

I know that I am loved 96.8%
I feel peaceful 90.3%
My life is worthwhile right now 80.6%

Environmental Context

I feel safe here 87.1%
I like my room to be quiet 87.1%

Social Context

A special person(s) makes me feel cared for 96.8%
I’m ok with my personal relationships 93.5%
My nurse gives me hope 90.3%

Research Question 3

The Functional Independence Measure (FIM)™ was used to answer the research question, “What is the CCI patients’ level of therapeutic physical activity, on admission to the LTACH and one month after admission?” This instrument was chosen to represent therapeutic physical activity in the CCI because it is a reliable
measure of patient progress commonly used by Physical and Occupational Therapists at long-term care centers (Dodds, Martin, Stolov & Deyo, 1993), including the study site LTACH.

The 18-item instrument measures the level of independence a person exhibits in personal activities of daily living (self-care, sphincter control, transfers, and locomotion) as well as communication and cognition. Total scores range from 18 (lowest possible function) to 126 (highest level of function). An interrater reliability analysis using the Kappa statistic was performed to determine consistency of ratings between the researcher and the physical therapist (Kappa = 0.774, p < .01), and indicated an acceptable level of agreement (Landis & Koch, 1977). In this study, the Cronbach’s alpha for the FIM total was .870. The test-retest reliability was calculated for all participants (n = 24); the result was acceptable (r = 0.61, p = .002). It was recalculated after removing two participants whose study intervals were considered outliers (14 days & 156 days); the resulting correlation was also acceptable (r = 0.62, p = .003).

For the purposes of this study, the researcher focused on total scores. However, analyses of the subscales of self-care, transfers and locomotion were also completed as variables of interest to the CCI population because they are influential in determining discharge disposition (Daly, Douglas, Kelley, O’Toole & Montenegro, 2005). Specific items that address self-care include eating, grooming and bathing; those that address transfer mobility assess the ability to
transfer to a chair or the commode; locomotion mobility items are concerned with a patient’s ability to walk, with or without assistive devices.

Table 7 shows the therapeutic physical activity experience for this sample. As expected, there was improvement in all but one aspect of physical function from baseline to follow-up; paired $t$-tests were calculated to determine whether these improvements were statistically significant. Participants at baseline had a mean total FIM score of 77.63 (range 42-126, SD 25.30). On follow-up, the mean total score for the sample increased to 99.21 (range 43-126, SD 27.93); this was statistically significant ($t = 5.859, p < .001$). In addition, participants’ scores for self-care, transfers and locomotion also increased significantly over time ($t = -4.99, -5.39, -5.16$, respectively; $p < .001$ for each); the improvement in sphincter control was also statistically significant ($t = -3.01, p < .01$). There was no significant change in communication or cognition over time, as was expected, due to the eligibility criteria regarding these functions.
Table 7

Therapeutic Physical Activity (FIM Scores) in the CCI – Baseline and Follow-up

<table>
<thead>
<tr>
<th>FIM Component</th>
<th>Baseline</th>
<th>Follow-up</th>
<th>t (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(possible)</td>
<td>M (range; SD)</td>
<td>M (range; SD)</td>
<td></td>
</tr>
<tr>
<td>Total (126)</td>
<td>73.58 (42-120; 16.08)</td>
<td>99.21 (43-126; 27.93)</td>
<td>- 5.859 (.000)**</td>
</tr>
<tr>
<td>Subscales</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care (42)</td>
<td>19.92 (6-42; 10.38)</td>
<td>31.42 (6-42; 12.80)</td>
<td>- 4.99 (.000)**</td>
</tr>
<tr>
<td>Mobility-transfer (21)</td>
<td>6.79 (3-18; 4.50)</td>
<td>13.17 (3-21; 7.52)</td>
<td>- 5.39 (.000)**</td>
</tr>
<tr>
<td>Mobility-locomotion (14)</td>
<td>4.54 (2-11; 3.20)</td>
<td>8.54 (2-14; 4.87)</td>
<td>- 5.16 (.000)**</td>
</tr>
<tr>
<td>Sphincter control (14)</td>
<td>7.92 (2-14; 5.28)</td>
<td>11.38 (2-14; 4.43)</td>
<td>- 3.01 (.006)*</td>
</tr>
<tr>
<td>Communication (14)</td>
<td>13.83 (12-14; .482)</td>
<td>13.92 (13-14; .282)</td>
<td>-1.45 (.162)</td>
</tr>
<tr>
<td>Cognition (21)</td>
<td>20.75 (17-21; .847)</td>
<td>20.79 (17-21; .833)</td>
<td>-1.00 (.328)</td>
</tr>
</tbody>
</table>

Note. * p < .01; ** p < .001

Research Question 4

An analysis of correlations between the CCICQ and FIM total scores was conducted to answer the research question, “What is the association between the CCI patients’ level of comfort and performance of therapeutic physical activity on admission to the LTACH and one month after admission?” At baseline there was a weak positive correlation between comfort and therapeutic physical activity that did not reach statistical significance ($r = .294, p = .162$). The four subscales of the
Comfort Questionnaire and the FIM subscales of self-care, mobility-transfer, and mobility-locomotion were explored in a secondary analysis, revealing statistically significant correlations between the total comfort and the mobility-transfer subscale of the FIM \( (r = .446, p = .029) \) and the FIM total and the physical subscale of the Comfort Questionnaire \( (r = .484, p = .017) \). Among the subscales, there were significant positive correlations between participants’ physical subscale and mobility-transfer scores \( (r = .496, p = .014) \), and environment subscale and mobility-locomotion scores \( (r = .424, p = .039) \). Table 8 illustrates the baseline correlations between holistic comfort and therapeutic physical activity in the CCI.
Table 8
Correlation Matrix – Holistic Comfort and Therapeutic Physical Activity – Baseline

<table>
<thead>
<tr>
<th></th>
<th>CCICQ total</th>
<th>Phys</th>
<th>Psych</th>
<th>Environ</th>
<th>Social</th>
<th>FIM total</th>
<th>Self-care</th>
<th>Transfer</th>
<th>Locomot</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCICQ total</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>.617**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psych-spirit</td>
<td>.850**</td>
<td>.313</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enviro</td>
<td>.624**</td>
<td>.173</td>
<td>.307</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Social</td>
<td>.779**</td>
<td>.384</td>
<td>.623*</td>
<td>.506*</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM total</td>
<td>.294</td>
<td>.484*</td>
<td>.167</td>
<td>.063</td>
<td>.159</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care</td>
<td>.153</td>
<td>.383</td>
<td>.033</td>
<td>.019</td>
<td>.063</td>
<td>.956**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer</td>
<td>.350</td>
<td>.496*</td>
<td>.191</td>
<td>.119</td>
<td>.279</td>
<td>.916**</td>
<td>.829*</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Locomot</td>
<td>.446*</td>
<td>.335</td>
<td>.288</td>
<td>.340</td>
<td>.424*</td>
<td>.846**</td>
<td>.727*</td>
<td>.877**</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. * p < .05 level, 2-tailed; ** p < .01 level, 2-tailed.

At follow-up, the correlation between comfort and therapeutic physical activity was statistically significant \( (r = 0.465, p = .022) \). In addition, there were significant correlations between total comfort and the mobility-transfer and mobility-locomotion subscales of the FIM \( (r = 0.481, 0.468, \text{respectively}; p < .05) \). The correlation between therapeutic physical activity and the physical subscale of the Comfort Questionnaire remained statistically significant \( (r = 0.489, p = .015) \), and the correlation between the therapeutic physical activity and psychospiritual subscale of the Comfort Questionnaire was statistically significant \( (r = 0.436, p = \ldots) \).
Three of the four Comfort Questionnaire subscales were significantly correlated to both the mobility-transfer and mobility-locomotion subscales of the FIM; the environmental subscale was not significantly correlated to any aspect of therapeutic physical activity on follow-up. Similarly, the self-care subscale of the FIM was not significantly correlated with any aspect of comfort on follow-up.

Table 9 illustrates the follow-up correlations between holistic comfort and therapeutic physical activity in the CCI.

Table 9  

*Correlation Matrix – Holistic Comfort and Therapeutic Physical Activity – Follow-up*

<table>
<thead>
<tr>
<th>n = 24</th>
<th>CCICQ total</th>
<th>Phys</th>
<th>Psych</th>
<th>Environ</th>
<th>Social</th>
<th>FIM total</th>
<th>Self-care</th>
<th>Transfer</th>
<th>Locomot</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCICQ total</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td>.880**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psych-spirit</td>
<td></td>
<td>.839**</td>
<td>.637**</td>
<td>1</td>
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<tr>
<td>Enviro.</td>
<td></td>
<td>.651**</td>
<td>.510*</td>
<td>.245</td>
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</tr>
<tr>
<td>Social</td>
<td></td>
<td>.875**</td>
<td>.741**</td>
<td>.711*</td>
<td>.456*</td>
<td>1</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>FIM total</td>
<td></td>
<td>.465*</td>
<td>.489*</td>
<td>.436*</td>
<td>.163</td>
<td>.400</td>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td>Self-care</td>
<td></td>
<td>.381</td>
<td>.410</td>
<td>.338</td>
<td>.195</td>
<td>.280</td>
<td>.965*</td>
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<tr>
<td>Transfer</td>
<td></td>
<td>.481*</td>
<td>.465*</td>
<td>.445*</td>
<td>.177</td>
<td>.468*</td>
<td>.941*</td>
<td>.860*</td>
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<tr>
<td>Locomot</td>
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<td>.468*</td>
<td>.463*</td>
<td>.463*</td>
<td>.101</td>
<td>.478*</td>
<td>.900*</td>
<td>.797*</td>
<td>.924**</td>
</tr>
</tbody>
</table>

*Note. *p < .05 level, 2-tailed; **p < .01 level, 2-tailed.*
Research Question 5

Research question 5 asked, “What are the differences among the CCI patients’ states of relatedness in terms of perceived level of comfort, and performance of therapeutic physical activity?” Analyses of variances (ANOVA) as well as independent-samples t-tests were performed to answer this question because participants did not represent all states of relatedness. Table 10 presents the results for the one-way ANOVAs.

Table 10

<table>
<thead>
<tr>
<th>Analysis of Variance for State of Relatedness on Comfort(^a) and Therapeutic Physical Activity(^b)</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort(^a)</td>
<td>6.663(^{**})</td>
<td>12.875(^{***})</td>
</tr>
<tr>
<td>Therapeutic Physical Activity(^b)</td>
<td>1.455</td>
<td>2.381</td>
</tr>
</tbody>
</table>

Note. \(^a\) CCICQ total; \(^b\) FIM total; \(^{**}p < 0.01; \(^{***}p < .001.\)

State of relatedness and holistic comfort

At baseline there was a significant difference in holistic comfort among the states of relatedness (\(F(3, 20) = 6.663, p = .003\)). Connected participants reported the highest level of comfort (\(m = 138.12, SD = 12.11\)); parallel participants reported a mean total comfort score of 134.00 (SD = 13.45); disconnected participants reported the lowest level of comfort (\(m = 104.00, SD = 11.45\)). The differences between those who were connected and those disconnected as well
as differences between those participants parallel compared to disconnected were statistically significant ($t = .468, t = 2.932$, respectively; $p < .05$). The differences in total comfort between those connected and those parallel were not statistically significant.

At follow-up the difference in total comfort (CCICQ) among the states of relatedness remained statistically significant ($F(3, 20) = 12.875, p = .000$). Post hoc testing indicated that, once again, those who felt disconnected reported lower total comfort scores ($m = 117.86, SD = 9.65$) than those in any other state of relatedness.

**State of relatedness and therapeutic physical activity**

The differences in baseline FIM scores among the states of relatedness were not statistically significant ($F(3, 20) = 1.455, p = .247$). Participants who felt connected had a mean score of 79.06 (SD = 22.38). Participants who felt an overall state of parallelism had a mean score of 65.33 (SD = 18.23). Those who felt disconnected had a mean score of 59.67 (SD = 15.69).

Differences in follow-up FIM scores among the states of relatedness did not reach statistical significance ($F(3, 20) = 2.381, p = .100$). Participants who characterized connectedness had a mean FIM of 106.07 (SD 24.26), while those who characterized disconnectedness had a mean score of 88.71 (SD = 28.79).

Because of the non-normal distribution of the variable ‘state of relatedness’, non-parametric analyses were conducted. The Kruskal-Wallis
findings at baseline and at follow-up were comparable to the ANOVAs for comfort and therapeutic physical activity.

Summary

The research questions and results provide evidence that relationships, especially as they influence the CCI patient’s state of relatedness, have important implications for his or her holistic comfort and, to a lesser extent, therapeutic physical activity. The use of social network analysis with this sample has enhanced our understanding of relationships of importance to the CCI patient over the course of his or her illness, in terms of roles and frequency of contact. Further discussion of these findings will be presented in Chapter V.
Chapter V

Discussion

This chapter provides an interpretation of the study’s finding and their significance for nursing knowledge and practice. An evaluation of the study model is presented. Limitations of the study are discussed and suggestions for future research are made.

Sample Description

This study sample is comparable to the Chronically Critically Ill (CCI) population as described in the literature in terms of mean age, gender proportion, reasons for ICU admissions, and the presence of multiple comorbidities (Daly, Douglas, Kelley, O’Toole & Montenegro, 2005; Unroe, et al., 2010). Minorities were under-represented in this sample with only 4.2% reported (African-Americans). There is conflicting evidence that African-American patients are enrolled in studies less often than whites (Wendler, et al., 2005; Cooke, et al., 2010). However, there is evidence in the literature of higher mortality rates among non-whites following critical illness (Quality of Life After Mechanical Ventilation in the Aged Study Investigators, 2002; Barnato, Alexander, Linde-Zwirble & Angus, 2008), potentially reducing the number of minority patients available for study recruitment, one possible explanation for the small percentage of minorities in this study.
CCI Patients’ Description of Relationships

A great deal of literature has described the family experience of having a loved one who is critically ill. This study gives voice to the CCI patients’ perspective and provides a unique description of relationships with family and friends, health professionals, and objects, during a particularly challenging period in his or her recovery. This description is presented in terms of CCI patients’ states of relatedness and social network features.

States of relatedness. There was a slight trend away from a sense of connectedness over time (70% at baseline, 63% at follow-up); possibly mirroring the chronicity of critical illness whereby supportive family members and friends are compelled to return to jobs and other responsibilities, decreasing the amount of time spent with the patient. At baseline, three participants’ states reflected a sense of disconnectedness; this number increased to six on follow-up, although this was not statistically significant. This finding supports the author’s earlier speculation that a prolonged critical illness may provoke a relationship transition from some degree of physical and psychological consistency to inconsistency, thus detracting from individual comfort. These findings are supported by Engström and Söderberg (2007) and Gardner and colleagues (2005): critically ill patients rely heavily on close relatives for confirmation, motivation, and physical assistance to continue the daily struggle for recovery. When the recovery from critical illness is protracted, the CCI patient’s source of confirmation and
motivation may be increasingly absent, directly and indirectly (phone calls, cards, etc.) leaving him or her less connected.

Interestingly, while overall states of relatedness among the network analysis participants were equally divided among connectedness, parallelism and disconnectedness, their specific states of relatedness were predominantly connected (75.9% at baseline; 81.2% on follow-up). No specific relationship was considered enmeshed or disconnected at baseline, but there were two enmeshed relationships present on follow-up. Thus, it appears that network analysis participants were effectively able to conceptualize the dimensions of relatedness from an overall perspective as separate from specific relationships, taking into consideration comforts and struggles unique to each relationship.

Although there were no significant associations between specific state of relatedness and type of relationship, or frequency of contact at baseline, on follow-up, the association between state of relatedness and frequency of contact was statistically significant. This finding is supported by the findings of Engström and Söderberg (2007) and Gardner and colleagues (2005); that is, there may be a time-spent-together element that influences a CCI patient’s state of relatedness with specific important contacts.

**Network Features.** This is the first known study to employ SNA to quantify and describe individual CCI patients’ relationships. Social Network Analysis is particularly useful as a way to understand network features such as which persons or objects are of importance to patients during the illness and how
often the identified person or object was in contact with the CCI patient. The social network of the CCI participant consisted mainly of relatives such as spouses, siblings and children. Few participants reported health care professionals as important relationships, and only one participant reported an object (nature) as an important relationship. Examination of available secondary responses suggests a similar pattern; no one reported health care professionals as important relationships during the patient’s illness, and just one secondary participant reported an object (God) as important during that time. This is not surprising since family and friends have consistently been in the foreground of patients’ minds in studies of social support. Hupcey’s qualitative study of ICU patients’ perceptions of social support (2001) revealed a primary theme on the importance of having a close family member or friend with them at all times. Nurses and other hospital staff were viewed as satisfactory support stand-ins, however, when family or friends were not available. In Fredriksen and Svensson’s qualitative study with 6 former ICU patients (2010), the patients’ significant others were spouses, children, parents and close friends. Results from Löf, Bergrren, and Ahlström’s qualitative study (2008) with eight ICU patients at 3 and 12 months after the initial illness support the current study’s finding that participants infrequently named hospital staff among important relationships. In focused interviews, patients could not recall names or faces of any staff, but they consistently characterized the staff as being helpful, encouraging, and instrumental in remaining motivated to recover. Thus, although patients in this
study did not usually identify staff members among important relationships, it is likely they considered them important to recovery.

CCI network analysis participants reported frequent contact with relationships important to them, choosing “somewhat often” or “very often” to describe the frequency of contact in the preceding three days nearly 96% of the time at baseline, and 90% on follow-up. This contradicts the author’s apriori hypothesis that the CCI may be prone to relationship disruption because of environmental and patient-care factors; however, it is noteworthy that participants were instructed to consider contact in the form of physical presence as well as telephone calls, greeting cards and letters. Furthermore, the typical disruptions of the ICU experience (mechanical ventilation, altered levels of consciousness, imposed visiting hour restrictions) were less of an obstacle in the long-term acute care hospital (LTACH) setting.

The comfort experience during CCI

This study investigated the CCI patient’s holistic level of comfort, on admission to the LTACH and one month after admission. The body of literature to date has focused primarily on symptoms such as pain, fatigue, and anxiety (Li & Puntillo, 2006; Nelson, et al., 2007), with less of a focus on such things as environmental safety, patient-physician communication, and existential concerns, as broader aspects of the human comfort experience. This is one of the first studies of CCI patient comfort that conceptualized comfort beyond absence of discomfort. The theoretical definition of comfort used in this study was the
immediate state of being strengthened that occurs when one’s need for relief, ease, and/or transcendence is met (Kolcaba, 1992), and was operationalized to the four contexts of comfort: physical, psycho-spiritual, environmental, and social. In this way, the concept takes on an holistic emphasis that is relatively new to the CCI population. When queried about comfort across these domains, several participants expressed surprise, some became uncomfortable. One participant stated, “I’d never thought of my comfort that way before; but it makes sense.”

CCI patients in this study expressed a moderate amount of overall comfort; subscale scores suggested they were most comfortable in the context of environment, which addressed features such as feeling safe, having enough privacy, and the temperature of his or her room. Conversely, participants were least comfortable in the physical context of the concept, which addressed features such as rest and sleep, pain experience, and ease of breathing. These findings augment others’ regarding the symptom burden in the CCI (Li & Puntillo, 2006; Nelson, et al., 2007; Roberts, Rickard, Rajbhandari, &Reynolds, 2007). Approximately 64% of participants in Nelson and colleagues’ (2004) study of symptoms experienced by the CCI reported pain, although the majority indicated they experienced it rarely or occasionally, and were not overly bothered by it (rated “not at all”, “a little bit” or “somewhat”). By comparison, participants in Nelson’s study were more distressed by fatigue, hunger, thirst, and difficulty communicating while on the mechanical ventilator. Li and
Puntillo’s study of ICU patient experiences (2006) mirrors those of Nelson’s. In their investigation, 83% of participants reported a moderate amount of general discomfort. Specific symptoms experienced were anxiety (87%), tiredness (87%), and thirst (80%); pain was not a significant source of discomfort.

In an effort to better understand what distresses and what strengthens the CCI patient, it is essential to enhance the description of the comfort experience from an holistic perspective. While the presence or absence of pain was not directly assessed in this study, the question of whether pain was difficult to endure was. The majority of participants did not feel the pain was difficult to endure. Furthermore, most agreed or strongly agreed that they could “rise above” any pain they may experience. Coupled with strongly affirmative responses regarding strength of spirituality, and the belief that “my God is helping me”, this points to an holistic comfort experience in the CCI, whereby he or she is strengthened across multiple domains. In this way, challenges to comfort in one domain, e.g. physical, may be overcome, or ameliorated by resources from another, e.g. psycho-spiritual or social.

The Comfort Questionnaire item that was inserted as a particular concern for critically ill patients, “I feel safe here”, yielded an affirmative response by 87% of the sample at baseline. In Hupcey’s qualitative study of critically ill patients (2001), this sense of safety was directly related to the presence of family members and friends, and staff who conveyed a demeanor of competence. This
study’s findings of a significant correlation between states of relatedness and overall comfort provide empiric support for Hupcey’s link.

**Therapeutic physical activity during CCI**

According to Nierman (2002), the greatest desire of CCI patients is “to survive the critical illness and to quickly recover without significant lasting damage or loss of function or quality of life” (Nierman, 2002, p. 486). However, in this study, data comparing living arrangement prior to ICU admission and discharge disposition suggest that, like other studies of CCI outcomes, participants had not returned to “normal” during the study period, despite significant improvement in physical function, as measured by the FIM. Examination of the self-care, mobility-transfer and mobility-locomotion subscales reveals most participants had a long way to go before independence could be realized. The mean scores for these subscales point to an ongoing need for at least minimal assistance with everyday activities, such as getting meals, dressing, going to the bathroom, and ambulating.

These findings are supported by Choi’s investigation of CCI patient’s caregiver distress (Choi, Donahoe, Zullo & Hoffman, 2011). In their study, 64% of the patients had not returned to their baseline functional status in the 6-month study period, although functional status progressively improved over time. Further, in Unroe and colleagues’ 1-year study of CCI outcomes (2010), more than 40% of those who survived the index hospitalization remained at least moderately dependent upon others for basic care at the 1-year mark; 21% were
considered completely dependent. Thus therapeutic physical activity levels often remain reduced and disconcerting well-beyond this study’s 1-month follow-up of CCI patients. There is growing support for the initiation of a progressive mobility protocol for critically ill patients (Winkleman, Higgins & Chen, 2005; Chiang, Wang, Wu, Wu & Wu, 2006; Timmerman, 2007; Schweickert, et al., 2009), but further research is needed to determine the implications of prolonged disability and additional interventions to improve functional outcomes following chronic critical illness.

The Role of Relationships During CCI

Research Question 5 provides for an examination of the study model. Results suggest that the association of state of relatedness to holistic comfort was supported, but the association of state of relatedness to the health-seeking behavior of therapeutic physical activity was not. Further, the association between comfort and therapeutic physical activity is supported, although it appears that it is primarily a function of comfort in the physical context.

State of relatedness and comfort. In this study, the majority of participants reported an overall state of relatedness that was associated with higher levels of comfort derived from involvement with all of his or her relationships. The association between state of relatedness and holistic comfort was positive and statistically significant. When the baseline and follow-up states of relatedness were dichotomized according to high or low comfort resulting from involvement, an analysis congruent with the conceptual model’s focus on
the comfort experience of the CCI, the association remained statistically significant. This supports the model’s assertion that states of relatedness are associated with holistic comfort during CCI. Further, this association is congruent with results from Roberts, Rickard, Rajbhandari, and Reynolds’ (2007), whose ICU participants described relationship-based comfort themes of feeling secure, being assured by a nurse’s touch, and feeling peaceful, even in the midst of frightening and physically uncomfortable experiences.

**State of relatedness and therapeutic physical activity.** As described in Chapter II, Patusky (2002) proposed that, in subjects with chronic fatigue, certain states of relatedness, namely disconnectedness and parallelism, may be influenced by an individual’s energy levels and motivation to be involved. While disconnectedness appeared to contribute to feelings of isolation, parallelism seemed to serve as a cushion that allowed subjects to focus on their health and activities, which contributed to overall improvement. In this study, a small number of participants characterized an overall parallel state of relatedness, but analysis of the relationship between those states characterized by a low level of involvement (parallel, disconnected) and total FIM scores suggested the association was not significant and therefore does not support Patusky’s conclusion.

One plausible explanation for the lack of association between states of relatedness and therapeutic physical activity in this study is the number of potential confounding factors related to a patient’s physical recovery from his or
her illness. Hayes’ and colleagues’ extensive systematic review of outcome measures for the critically ill (2000) concluded it was impractical to summarize the outcomes of the critically ill in an overall sense, because of the lack of comparable studies with regard to types of patients included, actual outcome measures employed, and periods of patient follow-up. They emphasize that these irregularities are not unique to critical care patient research. Still, the number of outcomes evaluated in this report was substantial, and included respiratory, renal, physical, and overall quality of life, to name a few. Such broad categories and their numerous sub-categories attest to the multi-dimensional burden of critical illness and, indirectly, of chronic critical illness. It is not surprising, therefore, that this study did not detect a significant association between state of relatedness and therapeutic physical activity in the CCI.

Other researchers have made similar conclusions, although not specifically in the CCI. Consider Richmond, Kauder, Hinkle and Shults (2003), who conducted a 2 ½ year, prospective, correlational study to identify early predictors of long-term disability in patients who experienced serious, non-central nervous system injuries (n=63). Long-term disability was defined as “limitation in socially defined roles and tasks expected of an adult in a socio-cultural environment” (p.197), which is congruent with the therapeutic physical activities in this study, especially self-care and mobility. A primary concept of interest was social support, measured by assessing patients’ perception of who they could count on during challenging times and how satisfied they were with
support received. The authors concluded that social network factors had no significant correlation to incidence of long-term disability.

Eriksson and Bergbom reported comparable findings from their study examining the impact of visits (frequency and duration) on ICU patient outcomes such as length of stay, duration of mechanical ventilation, and mortality (2007). Although the study was conducted in the acute care setting, patients’ average length of ICU stay was approximately 10 days, average duration of mechanical ventilation was 9 days and average hospital length of stay was slightly longer than 30 days, common characteristics of the CCI. Thus their findings can corroborate this study’s result that states of relatedness did not affect physical outcomes in a significant way.

**Comfort and therapeutic physical activity.** At baseline, there was a weak positive correlation between comfort (CCICQ) and therapeutic physical activity (FIM) \(r = .294, p = .162\), although it was not statistically significant. However, there was a statistically significant correlation between total comfort and the mobility-locomotion subscale of the FIM \(r = .446, p < .05\). In addition, the physical comfort subscale score was significantly correlated to the FIM total score and the mobility-transfer score \(r = .484, r = .496\), respectively; \(p < .05\). The environmental comfort subscale score was also significantly correlated to the mobility-locomotion subscale of the FIM \(r = .424, p < .05\).

On follow-up, comfort and therapeutic physical activity in this study were more strongly associated. Total comfort scores correlated significantly with the
FIM total score \( (r = .465, p < .05) \) and the mobility-transfer and mobility-locomotion scores \( (r = .481, .468, \text{respectively}; p < .05) \). The physical subscale of the Comfort Questionnaire remained significantly correlated with the FIM total, mobility-transfer, and mobility-locomotion subscales. It seems that the physical context of holistic comfort is most closely associated with therapeutic physical activity in the CCI. In addition to the experience of pain, this subscale takes into account ease of breathing, whether he or she feels good enough to do some things for him- or herself, and ability to rest or relax. When one considers these aspects of the physical domain of comfort in light of others’ findings regarding the impact of dyspnea and fatigue (Higgins, 1998; Meek & Lareau, 2003; Nelson, et al., 2004) on functional recovery from illness, it is not surprising that this study would yield a similar connection. Thus, there is plausible evidence to support the study model’s assertion of an association between holistic comfort and the health-seeking behavior of therapeutic physical activity.

**Limitations**

**Initial eligibility criteria**

After 6 months of data collection, and in consultation with the nursing staff at the LTACH, it was decided that the inclusion criterion regarding the maximum LTACH 14-day length of stay was limiting the number of eligible patients for recruitment into the study. The CCI patient experience often included repeated episodes of physiological instability, transfers (involving short re-admissions to acute care or outside facilities and return to the LTACH),
fatigue, and/or cognitive issues. The researcher found that these issues sometimes eventually resolved, but frequently did so after the criterion 14-day cut-off. Therefore an amendment was approved to modify the maximum length of stay criterion to read “CCI patients who have been continuously institutionalized since their critical illness episode and have been at the LTACH at least 48 hours”. This allowed a greater window of opportunity for a CCI patient to be eligible to participate in the study.

The drawback to this more liberal approach was a greater variation in enrolled patients’ overall length of illness when baseline and follow-up measures were conducted. Thus, comparisons of patient comfort and therapeutic physical activity were not as precise as they would have been if more stringent criteria had been applied. However, the complexity and variability of the human response to critical illness, well-described elsewhere in this paper, inherently make the application of such stringent criteria impractical, at best. Future research efforts could employ a purposive, stratified sampling method that would allow direct comparisons based on the chronicity of illness.

Sample size

Main study and SNA sample. The researcher proposed to enroll up to 60 CCI participants, 15 of whom would be consented to complete Social Network Analysis measures in addition to the CCICQ and VMR-overall instruments. Participants who completed baseline and follow-up measures comprised the final sample of 24; 6 of whom completed the additional network analysis
measures. Patient experiences of neurocognitive compromise, hemodynamic instability and condition deteriorations requiring transfers back to an acute ICU, and fatigue were but a few of the obstacles to enrollment encountered over the 15-month recruitment period. While these experiences were not foreign to the CCI population, the resulting small sample size prevents generalization of findings beyond this sample. Future studies using larger samples will serve to confirm or negate this study’s findings. In the meantime, because this study was conducted to advance our knowledge of the role relationships play during chronic critical illness, its findings are an important initial contribution to nurses’ efforts to facilitate interpersonal relationships and promote comfort and therapeutic physical activity in CCI patients.

**Secondary participants to the SNA sample.** In an attempt to provide a full description of the CCI patients’ social network, particularly as it relates to relationships perceived as important to the patient, recruitment of secondary participants was undertaken. The primary method of establishing contact was for the researcher to leave a complete packet of information, including a consent form and questionnaire, for the potential secondary in a prominent place in the CCI patient’s room. An invitation letter in the packet requested the potential participant to contact the researcher via telephone or email to discuss the study, complete the informed consent document and return it, along with the completed questionnaire, to the researcher using a pre-addressed, stamped envelope. The success of this recruitment method was very limited, despite the
use of multiple methods to make contact with potential secondary participants once a packet had been left in the CCI patient’s room. Other researchers have encountered similar obstacles in indirect recruitment of participants in the critical care setting. In Novak’s study of hospice patients and their caregivers (Novak, Kolcaba, Steiner & Dowd, 2001), incomplete data sets resulted when the research assistant left questionnaires for caregivers (potential secondary participants) to complete at later dates. This was done where caregivers were not present at the time of data collection. This method of data collection was ineffective for participants who were experiencing challenging circumstances, much like those whose family member had been critically ill for a prolonged period. Ideally, data collection with potential participants should be personally administered. Recent evidence presented by Choi and colleagues suggests that caregivers of the CCI experience significant lifestyle restrictions of even the most basic of activities, such as sleeping, caring for self, and completing household chores (Choi, Donahoe, Zullo & Hoffman, 2011). In this study, potential secondary participants who declined to consent often cited feelings of being overwhelmed with the patient’s condition and needs and stress over finances and job demands. In future research, it will be important to find ways to involve those who are important to the CCI participant without contributing to his or her anxiety or burden of responsibility.
Implications for Practice and Policy

Relationships and their contribution to comfort

Results from this study confirm that the holistic comfort experience of the CCI patient is enhanced by a sense of connectedness that is not completely dependent upon physical contact with important relationships. Greeting cards, phone calls, and other indirect forms of involvement can contribute to states of relatedness as well. For the CCI, out of sight is not out of mind; remembering that, and helping the patient to remain mindful of those important to him or her may foster an ongoing sense of connectedness, especially when the critical illness is very lengthy. Nurses may also consider ways for family and friends to easily stay in contact with the CCI patient, directly or indirectly, as the days of illness lengthen to weeks and months. In doing so, nurses can help to minimize any sense of disconnectedness that CCI patients may experience.

What is more, aspects of comfort, particularly in the physical domain, play an influential role in improved therapeutic physical activity. As this study demonstrated, physical comfort is not merely the absence of pain. Indeed, the CCI patient’s pain may be among the least bothersome experiences, or at least it may be something he or she feels strengthened to transcend. So nurses may have greater success in promoting holistic comfort by attending to other sources of discomfort, or suffering: fatigue, difficulty resting and poor sleep quality.
“Life is worthwhile to me right now”

The majority of participants agreed or strongly agreed that life remains worthwhile and nurses are a source of hope every day. Whether or not these patients are aware of the current outcome statistics for the CCI is not known. What this study suggests is that, even with all that he or she has been through, the effort has been, and will continue to be, worth it. This perspective can inspire nurses to keep offering hope, even when, to us, it seems a hopeless situation. Conversely, such a perspective may conflict with Unroe and colleagues’ findings, and their encouragement for providers to carefully temper the optimism of patients and family members when conducting discussions of ongoing life support measures. Without further research we cannot know the inner strengths a patient may possess, nor his or her motivations to persevere in the face of very discouraging circumstances.

Social networks of the CCI

The Social Network Analyses conducted in this study suggests that, while nurses and physicians, individually and collectively, are recognized and widely respected for their contributions to life support, it is family and friends who are important to the CCI. Thus, nurses can best serve CCI patients by fostering strong working relationships with their family and friends. Since comfort is germane to the practice of nursing, any non-pharmacological means of promoting comfort in so challenging a population as the CCI should be employed.
Implications for policy

The findings of this study support the idea of open visiting hours for critical care units. The body of literature regarding this issue increasingly points to benefits to critically ill patients and their families when ICUs are open and welcoming to visitors at all times, even during patient resuscitation (Davidson, et al., 2007; Olsen, Dysvik & Hansen, 2009; Cypress, 2010; Doolin, Quinn, Bryant, Lyons & Kleinpell, 2011).

Judicious development of policies that intentionally integrate close family and friends in critically ill patients’ care represent an opportunity for hospitals to promote holistic comfort, patient and family satisfaction, and CCI outcomes. Such policy development must accompanied by efforts to generate an empirical basis for ongoing refinement and improvement.

Along with open visiting hours is the need to implement staff education initiatives to facilitate interpersonal connections and communication with one another and family members of critically ill patients while minimizing negative impact on staff health. This is important, since there has been evidence that ICU nurses experience stress or frustration when they feel unprepared to answer questions from the family or when communication is poor between the physician and the family (Davidson, et al., 2007).

Recommendations for Future Research

There are several directions in which future research of the role of relationships during chronic critical illness should proceed. First and, perhaps
foremost, is the need to replicate this study with a larger sample size. In this way, associations between states of relatedness, comfort and therapeutic physical activity could be further established. Also, the possibility of an indirect association between states of relatedness and therapeutic physical activity could be explored.

Another direction for future research could be to investigate the impact of different types of relationships on health-seeking behaviors. Although this study did not uncover a statistically significant association between states of relatedness, the prime importance of family and friends was made clear. Research to establish a base of evidence that incorporates these individuals in health professionals’ efforts to assist patients through physical mobility protocols and therapies is needed. In this way, CCI patients may realize greater success in reclaiming independence.

Many of the participants in this study indicated difficulty resting and inability to sleep soundly. These are not new issues for the CCI, but their responses renew the call for research to develop interventions that enhance a relaxed environment which promotes rest and sleep.

Social network analysis (SNA) is in its infancy as a valuable tool for understanding and improving the CCI patient relationship experience. Research that improves methods and interpretation is needed. Other industries have successfully utilized SNA to streamline operations, improve communication, and expose effective interpersonal interactions; these benefits could be of immense
use to nurses and health care as well. For example, Lurie, Fogg and Dozier’s observational study of three ICU patients’ social networks (2009) highlighted one who had been in for two weeks (CCI). This patient experienced a decreased number and frequency of contacts with ICU health-care provider team members over time. The authors did not explore relationships from the patient’s perspective, although “key family” was included. Further research is needed to determine whether the reduction in network density is typical of CCI, what impact it may have on patient outcomes.

Lastly, future research should examine ways that CCI consider life worthwhile. In the midst of mechanical ventilators, drainage tubes and feeding tubes, challenges to effective interpersonal communication, skin breakdown, disrupted rest and sleep, the participants in this study insist life is worthwhile. Studies to illuminate how and why such an existence is of value can provide a crucial counter-argument to those who question continuing to provide physiological support. Furthermore, such information may compel health care professionals to focus on ways to facilitate and understand CCI patients’ expressions of value and meaning during the prolonged days of illness.

Summary

This study examined the role of relationships during chronic critical illness from the patient’s perspective. In this way, it has contributed quantitative evidence to the body of nursing knowledge about how CCI patients describe important relationships, the associations among states of relatedness, holistic
comfort and therapeutic physical activity. This study also is one or the first to use social network analysis as an additional method of understanding how and to whom CCI patients are connected. Relationships with family and friends are of primary importance, but nurses continue to be a source of hope and inspiration whose impact must not be overlooked. Further research is necessary to continue to build upon this study and the existing qualitative understanding of what relationships mean to the CCI. In this way, nurses can strengthen their commitment to Nightingale’s commission to make observations and take actions that serve to save patients’ lives as well as increase their health and comfort.
CONSENT FOR INVESTIGATIONAL STUDIES (Social Network Analysis – primary participant)

Project Title: The role of relationships during chronic critical illness.

Principal Investigator: Debra Lee, BSN

You are being asked to participate in a research study because you recently have been hospitalized in an Intensive Care Unit for more than six days. Please read this form and ask any questions that you may have before agreeing to be in the research.

Researchers at Case Western Reserve University, Frances Payne Bolton School of Nursing are conducting this study.

Background Information
The purpose of this study is to understand how people who have been critically ill for a long period view their relationships during their illness. This research also will explore how relationships may have a bearing on your comfort and physical functioning.

Approximately 15 people will participate in this study.

Procedures
If you agree to participate in this research, we will ask you to do the following things:
- Complete four paper-and-pencil questionnaires about your relationships and your feelings of comfort.
- Complete a test that measures your physical and mental abilities. This is the Functional Independence Measure, the same test that Physical Therapists at this facility use each week to evaluate your progress.

Participation will require two sessions, one today and a second, follow-up session in about one month. Each session will last about one hour. The researcher will help you complete all tests. Today, we will complete all the tests here in your room. In one month, the tests will be repeated; at that time, you and the researcher will determine the best place to meet to conduct the second session of testing.

Risks to Being in the Study
There is a small chance that you may experience some emotional discomfort while answering the questionnaires. If you do experience emotional discomfort, you may take a break from answering the questions or choose to permanently stop answering questions.
**Benefits to Being in the Study**
There is no direct benefit to you. The benefit of participation is the possibility of helping to improve our understanding of the importance of relationships during chronic critical illness.

**Confidentiality of Research Information**
There is a risk to participants of loss of privacy. The privacy of your research information will be protected as much as possible. In addition to conducting all tests in a private location, the researcher will code your name and personal information and keep it in a locked file cabinet that only the researcher can access. In addition, the researcher will create passwords for any electronic information generated; the researcher will be the only person who will know these passwords.

**Compensation**
No compensation will be provided to you as a participant.

**Costs to participants**
There will be no cost to you as a participant in this study.

**Alternatives to participation**
You may choose not to participate. If you choose not to participate, but want to discuss your relationships with another professional (staff, administrator, clergy, for example), the researcher will inform the staff of your request so that arrangements can be made for you.

**Privacy of Protected Health Information**
The Health Insurance Portability & Accountability Act (HIPAA) is a Federal law that helps to protect the privacy of your health information and to whom this information may be shared within and outside of University Hospitals. This Authorization form is specifically for a research study entitled “The role of relationships during chronic critical illness” and will tell you what health information (called Protected Health Information or PHI) will be collected for this research study, who will see your PHI and in what ways they can use the information. In order for the Principal Investigator, Debra Lee, BSN, and the research study staff to collect and use your PHI, you must sign this authorization form. You will receive a copy of this signed Authorization for your records. If you do not sign this form, you may not join this study. Your decision to allow the use and disclosure of your PHI is voluntary and will have no impact on your treatment at University Hospitals. By signing this form, you are allowing the researchers for this study to use and disclose your PHI in the manner described below.

Generally the Principal Investigator and study staff at University Hospitals and Case Western Reserve University who are working on this research project will know that you are in a research study and will see and use your PHI. The researchers working on this study will collect the following PHI about you: information related to why you needed to be in an Intensive Care Unit and a Long Term Acute Care Hospital, medications you received, whether you were on a breathing machine (ventilator), and any other illnesses
you have. This PHI will be used to understand how people who have been critically ill for a long period view their relationships during their illness. This information will also be used to explore how relationships may have a bearing on your comfort and physical functioning. Your access to your PHI may be limited during the study to protect the study results.

Your PHI may also be shared with the following groups/persons associated with this research study or involved in the review of research: members of Ms. Lee’s dissertation committee (Dr. Patricia Higgins, Dr. Carol Musil, Dr. Mary Quinn-Griffin, and Dr. Christopher Burant); University Hospitals, including the Center for Clinical Research and the Law Department; Government representatives or Federal agencies, when required by law.

Your permission to use and disclose your PHI does not expire. However, you have the right to change your mind at any time and revoke your authorization. If you revoke your authorization, the researchers will continue to use the information that they previously collected, but they will not collect any additional information. Also, if you revoke your authorization you may no longer be able to participate in the research study. To revoke your permission, you must do so in writing by sending a letter to Patricia Higgins, RN, PhD at 10900 Euclid Avenue, Cleveland, Ohio, 44106; If you have a complaint or concerns about the privacy of your health information, you may also write to the UH Privacy Officer, Management Service Center, 3605 Warrensville Center, MSC 9105, Shaker Heights, OH 44122 or to the Federal Department of Health and Human Services (DHHS) at DHHS Regional Manager, Office of Civil Rights, US Department of Health and Human Services Government Center, JF Kennedy Federal Building, Room 1875, Boston, MA 02203. Complaints should be sent within 180 days of finding out about the problem.

The researchers and staff agree to protect your health information by using and disclosing it only as permitted by you in this Authorization and as directed by state and Federal law. University Hospitals is committed to protecting your confidentiality. Please understand that once your PHI has been disclosed to anyone outside of University Hospitals, there is a risk that your PHI may no longer be protected; however other Federal and State laws may provide continued protection of your information.

**Summary of your rights as a participant in a research study**

Your participation in this research study is voluntary. Refusing to participate will not alter your usual health care or involve any penalty or loss of benefits to which you are otherwise entitled.

If you decide to join the study, you can withdraw at any time and for any reason without penalty or loss of benefits. If information generated from this study is published or presented, your identity will not be revealed. In the event new information becomes available that may affect the risks or benefits associated with this study or your willingness to participate in it, you will be notified so that you can decide whether or not to continue participating. If you experience physical injury or illness as a result of
participating in this research study, medical care is available at University Hospitals Case Medical Center (UHCMC) or elsewhere; however, UHCMC has no plans to provide free care or compensation for lost wages.

**Disclosure of your study records**
Efforts will be made to keep the personal information in your research record private and confidential, but absolute confidentiality cannot be guaranteed. The University Hospitals Case Medical Center Institutional Review Board may review your study records. If your records are reviewed your identity could become known.

**Contact information**
________________________________________ has described to you what is going to be done, the risks, hazards, and benefits involved. The Principal Investigator, Debra Lee, can be contacted at 330-701-7845. You can also contact the Responsible Investigator, Dr. Patricia Higgins, at 216-368-8850. You can ask any questions you have now. If you have any questions, concerns or complaints about the study in the future, you can also contact them later.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; concerns regarding the study; research participant’s rights; research- related injury; or other human subject issues, please call the University Hospitals Case Medical Center’s Research Subject Rights phone line at (216) 983-5633 or write to: The Chief Medical Officer, The Center for Clinical Research, University Hospitals Case Medical Center, 11100 Euclid Avenue, Lakeside 1400, Cleveland, Ohio, 44106-7061.
**Signature**

Signing below indicates that you have been informed about the research study in which you voluntarily agree to participate; that you have asked any questions about the study that you may have; and that the information given to you has permitted you to make a fully informed and free decision about your participation in the study. By signing this consent form, you do not waive any legal rights, and the investigator(s) or sponsor(s) are not relieved of any liability they may have. A copy of this consent form will be provided to you.

____________________________ Date____________________________
Signature of Participant                                                         Printed Name of Participant

____________________________ Date____________________________
Signature of Person Obtaining Consent                                          Printed Name of Person Obtaining Consent

(Must be study investigator or individual who has been designated in the Checklist to obtain consent.)

____________________________ Date____________________________
Signature of Principal Investigator                                             Printed Name of Principal Investigator
CONSENT FOR INVESTIGATIONAL STUDIES (Social Network Analysis – secondary participant)

**Project Title:** The role of relationships during chronic critical illness.

**Principal Investigator:** Debra Lee, BSN

You are being asked to participate in a research study because someone you know or have worked with recently had been hospitalized in an Intensive Care Unit for more than six days and described you as important to him or her during the illness. Please read this form and ask any questions that you may have before agreeing to be in the research.

Researchers at Case Western Reserve University, Frances Payne Bolton School of Nursing are conducting this study.

**Background Information**
The purpose of this study is to understand how people who have been critically ill for a long period view their relationships during their illness. This research also will explore how relationships may have a bearing on the comfort and physical functioning of people who have been critically ill for a long period.

As many as 75 people will participate in this portion of the study.

**Procedures**
If you agree to participate in this research, we will ask you to complete a paper-and-pencil questionnaire about about relationships of importance to you during your relative/friend/patient’s present illness.

You will complete this questionnaire two times: today, and in one month. Today, the questionnaire is included with this consent form; you and the researcher will also determine the best way to contact you in one month, when the questionnaire will be repeated. You will need about ten minutes to complete the questionnaire each time.

**Risks to Being in the Study**
There is a small chance that you may experience some emotional discomfort while answering the questionnaires. If you do experience emotional discomfort, you may take a break from answering the questions or choose to permanently stop answering questions.
Benefits to Being in the Study
There is no direct benefit to you. The benefit of participation is the possibility of helping to improve our understanding of the importance of relationships during chronic critical illness.

Confidentiality of Research Information
There is a risk to participants of loss of privacy. The privacy of your research information will be protected as much as possible. In addition to conducting all tests in a private location, the researcher will code your name and personal information and keep it in a locked file cabinet that only the researcher can access. In addition, the researcher will create passwords for any electronic information generated; the researcher will be the only person who will know these passwords.

Compensation
No compensation will be provided to you as a participant.

Costs to participants
There will be no cost to you as a participant in this study.

Alternatives to participation
You may choose not to participate. If you choose not to participate, but want to discuss relationships of importance to you during your relative/friend/patient’s present illness with another professional (staff, administrator, clergy, for example), the researcher will inform the staff of your request so that arrangements can be made for you.

Summary of your rights as a participant in a research study
Your participation in this research study is voluntary. Refusing to participate will not alter your relative/friend/patient’s usual health care or involve any penalty or loss of benefits to which he or she is otherwise entitled.

If you decide to join the study, you can withdraw at any time and for any reason without penalty or loss of benefits. If information generated from this study is published or presented, your identity will not be revealed. In the event new information becomes available that may affect the risks or benefits associated with this study or your willingness to participate in it, you will be notified so that you can decide whether or not to continue participating. If you experience physical injury or illness as a result of participating in this research study, medical care is available at University Hospitals Case Medical Center (UHCMC) or elsewhere; however, UHCMC has no plans to provide free care or compensation for lost wages.

Disclosure of your study records
Efforts will be made to keep the personal information in your research record private and confidential, but absolute confidentiality cannot be guaranteed. The University Hospitals Case Medical Center Institutional Review Board may review your study records. If your records are reviewed your identity could become known.
Contact information

______________________________ has described to you what is going to be done, the risks, hazards, and benefits involved. The Principal Investigator, Debra Lee, can be contacted at 330-701-7845. You can also contact the Responsible Investigator, Dr. Patricia Higgins, at 216-368-8850. You can ask any questions you have now. If you have any questions, concerns or complaints about the study in the future, you can also contact them later.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about: concerns regarding the study; research participant’s rights; research-related injury; or other human subject issues, please contact University Hospitals Case Medical Center’s Chief Medical Officer at (216) 844-3695 or write to: The Chief Medical Officer, The Center for Clinical Research, University Hospitals Case Medical Center, 11100 Euclid Avenue, Lakeside 1400, Cleveland, Ohio, 44106-7061.
Signature
Signing below indicates that you have been informed about the research study in which you voluntarily agree to participate; that you have asked any questions about the study that you may have; and that the information given to you has permitted you to make a fully informed and free decision about your participation in the study. By signing this consent form, you do not waive any legal rights, and the investigator(s) or sponsor(s) are not relieved of any liability they may have. A copy of this consent form will be provided to you.

____________________________ Date ______________________________
Signature of Participant                                                   Printed Name of Participant

____________________________ Date ______________________________
Signature of Person Obtaining Consent           Printed Name of Person Obtaining Consent

(Must be study investigator or individual who has been designated in the Checklist to obtain consent.)

____________________________ Date ______________________________
Signature of Principal Investigator             Printed Name of Principal Investigator
Appendix C: Short Portable Mental Status Questionnaire

INSTRUCTIONS: Ask questions 1-10 in this list and record all answers. Ask question 4a only if patient does not have a telephone. Record total number of errors based on the ten questions. Refer to the reverse for scoring guidelines.

1. What is the date today? ____________________________
   Month     Day    Year

2. What day of the week is it? ____________________________

3. What is the name of this place? ____________________________

4. What is your telephone number? ____________________________
   4a. What is your street address? (Ask only if patient does not have a telephone)

   ___________________________________________________________________

5. How old are you? ____________________________

6. When were you born? ____________________________

7. Who is President of the United States now? ____________________________

8. Who was President just before him? ____________________________

9. What was your mother’s maiden name? ____________________________

10. Subtract 3 from 20 and keep subtracting from each new number, all the way down.

   COMMENTS

SCORING: * _______ Errors

   _______ * Adjustment Factor

   _______ TOTAL ADJUSTED SCORE

   _______ 0 – 2 Errors Intact Cognitive Functioning
   _______ 3 – 4 Errors Mild Cognitive Impairment
   _______ 5 – 7 Errors Moderate Cognitive Impairment
   _______ 8 – 10 Errors Severe Cognitive Impairment

Interviewer Signature:
________________________________________Date_______________
INTERVIEWER SCORING GUIDELINES

Ask the potential participant questions 1 through 10 in this list and record all answers. In order to be scored as correct, all responses must be given by the potential participant without reference to calendar, newspaper, birth certificate, or other aid to memory.

**Question 1** Scored as correct only when the exact month, exact date, and the exact year are given correctly.

**Question 2** Is self-explanatory.

**Question 3** Should be scored as correct if any correct description of the location is given. “my home”, correct name of the town or city of residence, or the name of the hospital or institution if subject is institutionalized, are all acceptable.

**Question 4** Should be scored as correct when the correct telephone number can be verified, or when the subject can repeat the same number at another point in the questioning.

**Question 5** Is scored as correct when stated age corresponds to date of birth.

**Question 6** Is to be scored as correct only when the month, exact date and year are all given.

**Question 7** Requires only the last name of the President.

**Question 8** Requires only the last name of the previous President.

**Question 9** Does not need to be verified. It is scored as correct if a female first name plus a last name other than subject’s last name is given.

**Question 10** Requires that the entire series must be performed correctly in order to be scored as correct. Any error in the series or unwillingness to attempt the series is scored as incorrect.

**Adjustment Factor:** *Subtract 1* from Error Score if subject had only grade school education. *Add 1* to Error Score if subject has had education beyond high school.

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Appendix D: Timeline for Administration of Measures

<table>
<thead>
<tr>
<th>Activity</th>
<th>Main Study participant</th>
<th>SNA primary participant</th>
<th>SNA secondary</th>
<th>One-month follow-up</th>
<th>Main Study participant</th>
<th>SNA primary participant</th>
<th>SNA secondary</th>
</tr>
</thead>
<tbody>
<tr>
<td>SPMSQ</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Demographics</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>VMR overall</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VMR specific</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>SNQ</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SNQs</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>CCICQ</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: 1 update as needed*
Appendix E: Demographic Questionnaire

1. Age (years): __________

2. Gender (circle one): M F

3. Race/ethnicity (select one):
   Hispanic _____; African-American _____; Caucasian _____; Other _____;

4. Living arrangement prior to ICU admission (select one):
   At home without paid assistance _____; At home with paid assistance _____;
   Assisted living facility _____; Nursing home _____;
   Rehabilitation hospital _____;

5. Reason for ICU admission: ______________________________________;

   *Reason for LTACH admission: ________________________________;

6. Comorbidities upon ICU admission (select all that apply):
   Diabetes _____; Heart disease _____; Renal insufficiency/failure _____;
   Cancer _____; COPD/lung disease _____;
   Other chronic illness (specify) ________________________________;

7. Location at time of interview (select one):
   LTACH _____; At home without paid assistance _____;
   At home with paid assistance _____; Assisted living facility _____;
   Nursing home _____; Rehabilitation hospital _____;
   Other location ________________________________;
8. Discharge disposition following long-term, acute-care hospital stay (select one):
   At home without paid assistance _____; At home with paid assistance _____;
   Assisted living facility _____; Nursing home _____;
   Rehabilitation hospital _____; Other location __________________________;

9. Predominant route of nutrition delivery (select one):
   Oral _____; Intravenous _____; Percutaneous/gastric _____;

10. Wound care measures: ______________________________________________;

11. Physical Therapy frequency: ____________, duration: ______________;

12. Occupational Therapy frequency: ____________, duration: ______________;

13. Mechanical ventilation (circle one): Yes   No

14. Analgesic administration ≤ 1 hour prior to interview (circle one): Yes   No
Appendix F: Visual Measure of Relatedness – Overall

Please answer the two questions below by making a mark on the line below the question at the point that matches how you feel.

Think about all of your relationships as they are now.

1. In these relationships would you say, overall, that you are:

   X------------------------------------------------------------------------------------------------X
   Not involved at all                                                                              Very involved

2. This amount of involvement makes you feel:

   X------------------------------------------------------------------------------------------------X
   Very uncomfortable        Very comfortable
Appendix G: Visual Measure of Relatedness - Specific

Please answer the two questions below by making a mark on the line below the question at the point that matches how you feel.

1. Think about your relationship with ______________ as it is now.
   In this relationship would you say, overall, that you are:

   X------------------------------------------------------------------------------------------------X
   Not involved at all                                                                   Very involved

2. This amount of involvement makes you feel:

   X------------------------------------------------------------------------------------------------X
   Very uncomfortable                                                                Very comfortable
Appendix H: Social Network Questionnaire

Relationships are an important part of our lives. Relationships with people and objects can take on different meanings at different times in our lives, such as during a critical illness. Please take a few moments to think about relationships of importance to you during your present illness and how often you have talked, or had contact those people or objects in the past few days.

On the next page, in the first column (Person/object), please identify seven people or objects of importance to you (by name) during your present illness.

In the second column (What is your relationship to this person/object?), place a check mark to indicate that person’s or object’s relationship to you. Then, if possible, specify the relationship (for example, if you mark Relative, is the Relative your sister?).

In the third column (How often), place a check to indicate how often you have talked, or had contact with them in the past few days.

This is an example of possible answers to these questions; your actual survey begins on the next page (page 2):

<table>
<thead>
<tr>
<th>Person/object</th>
<th>What is your relationship to this person/object?</th>
<th>How often have you had contact? (circle one)</th>
</tr>
</thead>
</table>
| 1. John Doe (*the first and last name of a friend/acquaintance of yours*) | ___ Relative; specify - ________________  
X  Friend/Acquaintance; specify - __friend__ (*John Doe is your friend__) | 1 = not at all  
2 = not often  
3 = somewhat often  
4 = very often |
| | ___ Health Care professional; specify - ________________  
___ Object; specify - ________________ | |

*Note: The text is copyrighted and protected by law.*
<table>
<thead>
<tr>
<th>Person/object</th>
<th>What is your relationship to this person or object?</th>
<th>How often have you had contact? (circle one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>2.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>3.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>4.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>5.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>6.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>7.</td>
<td>___ Relative; specify - _________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ______________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - _____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ___________________________</td>
<td>4 = very often</td>
</tr>
</tbody>
</table>
Appendix I: Social Network Questionnaire - Secondary

Relationships are an important part of our lives. Relationships with people and objects can take on different meanings at different times in our lives, such as during a critical illness. Please take a few moments to think about relationships of importance to you during your relative/friend/patient’s present illness and how often you have talked, or had contact those people or objects in the fast few days.

On the next page, in the first column (Person/object), please identify five relationships of importance (by first and last initials only, if a person) to you during your relative/friend/patient’s present illness, including the patient.

In the second column (What is your relationship to this person/object?), place a check mark to indicate that person’s or object’s relationship to you. Then, if possible, specify the relationship (for example, is the Relative your sister?).

In the third column (How often), place a check to indicate how often you have talked, or had contact with them, regarding your relative/friend/patient, in the past few days.

Below is an example of possible answers to these questions; your actual survey begins on the next page (page 2):

<table>
<thead>
<tr>
<th>Person/object</th>
<th>What is your relationship to this person/object?</th>
<th>How often have you had contact? (circle one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. R.A. (the first and last initials of a friend/acquaintance of yours)</td>
<td>___ Relative; specify - ________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>X   Friend/Acquaintance;</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>specify - friend (R.A. is your friend)____</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>___ Health Care professional;</td>
<td>4 = very often</td>
</tr>
<tr>
<td></td>
<td>specify - ________________________________</td>
<td></td>
</tr>
<tr>
<td></td>
<td>___ Object; specify - ________________________</td>
<td></td>
</tr>
<tr>
<td>Person/object</td>
<td>What is your relationship to this person or object?</td>
<td>How often have you had contact? (circle one)</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>1. Patient</td>
<td>_ Relative; specify - __________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ________________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - ___</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ____________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>2.</td>
<td>_ Relative; specify - __________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ________________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - ___</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ____________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>3.</td>
<td>_ Relative; specify - __________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ________________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - ___</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ____________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>4.</td>
<td>_ Relative; specify - __________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ________________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - ___</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ____________________________</td>
<td>4 = very often</td>
</tr>
<tr>
<td>5.</td>
<td>_ Relative; specify - __________________________</td>
<td>1 = not at all</td>
</tr>
<tr>
<td></td>
<td>_ Friend/Acquaintance; specify - ________________</td>
<td>2 = not often</td>
</tr>
<tr>
<td></td>
<td>_ Health Care professional; specify - ___</td>
<td>3 = somewhat often</td>
</tr>
<tr>
<td></td>
<td>_ Object; specify - ____________________________</td>
<td>4 = very often</td>
</tr>
</tbody>
</table>
Appendix J: Chronic Critical Illness Comfort Questionnaire

Thank you very much for helping us in the study of people who are chronically critically ill. Below are statements that pertain to your comfort right now. Four numbers (illustrated below) are provided for each question; please circle the number you think most closely matches your feeling. Relate these questions to your comfort at the moment you are answering the questions.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Strongly Agree</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My body is relaxed right now</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. My breathing is difficult</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3*. I have enough privacy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. There are those I can depend on when I need help....</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5*. I feel bloated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. I worry about my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7*. My beliefs give me peace of mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8*. My nurse gives me hope</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. I know that I am loved</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. My life is worthwhile right now</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. These surroundings are pleasant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. I have difficulty resting</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>13*. No one understands me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>14. My pain is difficult to endure</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>15. I feel peaceful</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>16. I sleep soundly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>17*. I feel guilty</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>18**. I feel safe here</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>19. I am nauseated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>20*. I feel scared in this room</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

CONTINUED ON NEXT PAGE...
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Strongly Agree</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.</td>
<td>I am afraid of what is next</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>22*.</td>
<td>I have a special person(s) who makes me feel cared for</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>I have experienced change(s) which makes me feel uneasy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>24*.</td>
<td>I like my room to be quiet</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>25*.</td>
<td>I would like to see my doctor more often</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>My mouth feels very dry</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>I’m okay with my personal relationships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>I can rise above my pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>The mood around here is depressing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>30*.</td>
<td>I am at ease physically</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>This chair(bed) makes me hurt</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>32*.</td>
<td>I think about my discomforts constantly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>33.</td>
<td>I feel confident spiritually</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>34.</td>
<td>I feel good enough to do some things for myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>35*.</td>
<td>My friends remember me with cards and phone calls</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>36*.</td>
<td>I feel out of place here</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>37*.</td>
<td>I need to be better informed about my condition</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>38.</td>
<td>I feel helpless</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>39*.</td>
<td>My God is helping me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>40*.</td>
<td>This room smells fresh</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>41.</td>
<td>I feel lonely</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>42*.</td>
<td>I am able to tell people what I need</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>43*.</td>
<td>I am depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>44*.</td>
<td>I have found meaning in my life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>45*.</td>
<td>The temperature in this room is comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>46.</td>
<td>I like it here</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
Appendix K: Functional Independence Measure

<table>
<thead>
<tr>
<th>No Helper</th>
<th>Helper</th>
</tr>
</thead>
</table>
| **7** = Complete Independence (timely, safely)  
**6** = Modified Independence (device) |
| **Modified Dependence** | **Complete Dependence** |
| **5** = Supervision | **2** = Maximal Assist (Subject ≥ 25%) |
| **4** = Minimal Assist (Subject > 75%) | **1** = Total Assist (Subject = 0% +) |
| **3** = Moderate Assist (Subject ≥ 50%) |

<table>
<thead>
<tr>
<th>Self Care</th>
<th>Admit (baseline)</th>
<th>Discharge (post)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Grooming</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. Bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. Dressing – upper body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. Dressing – lower body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F. Toileting</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sphincter Control**

| G. Bladder Management |                  |
| H. Bowel Management |

**Mobility (Transfer)**

| I. Bed, chair, wheelchair |          |
| J. Toilet |                |
| K. Tub, shower |              |

**Mobility (Locomotion)**

<table>
<thead>
<tr>
<th>L. Walk/wheelchair</th>
<th>W</th>
<th>W</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C</td>
<td>C</td>
</tr>
</tbody>
</table>

| M. Stairs |

**Communication**

<table>
<thead>
<tr>
<th>N. Comprehension</th>
<th>A</th>
<th>A</th>
</tr>
</thead>
<tbody>
<tr>
<td>O. Expression</td>
<td>V</td>
<td>V</td>
</tr>
</tbody>
</table>

**Social Cognition**

<table>
<thead>
<tr>
<th>P. Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q. Problem Solving</td>
</tr>
<tr>
<td>R. Memory</td>
</tr>
</tbody>
</table>

**Total FIM**
Letter of permission to recruit and interview patients receiving care

Dear Dr.

My name is Debbie Lee, from Case Western Reserve University Frances Payne Bolton School of Nursing. To complete my doctoral dissertation, I am conducting a research study about relationships during Chronic Critical Illness. Patients receiving care under your services at the Specialty Hospital at University Hospitals Extended Care Campus, in Chardon, Ohio, may be eligible to participate in this study. I am seeking your permission to recruit, enroll, and interview them according to the research protocol.

**Eligible participants** will be those patients who:
1. required ICU services for seven or more days (at the acute care hospital);
2. have been at this LTACH > 48 hours but < 14 days;
3. are 21 years of age or older;
4. understand and speak English.

Individuals on mechanical ventilation will be considered eligible if they are assessed as able to give consent and participate in the study (Short Portable Mental Status Questionnaire).

**Exclusion criteria will be:**
1. history of severe neurological insult as a result of trauma or stroke;
2. history of major psychiatric disorder; delirium experienced during or since ICU admission that has not resolved at the time of potential study participation; 
3. patients deemed inappropriate according to physician judgment.

**Data collection will be conducted in the participant’s current environment & consist of:**

1. researcher review of the enrolled participant’s medical record; 
2. completion of four brief questionnaires by the patient (assisted as needed by researcher); 
3. functional assessment by the researcher using the FIM.

In addition, persons named by the participant as important to him or her during this illness will be asked to complete a one-page questionnaire which should take less than five minutes. The questionnaires to be used in this study ask about participant involvement and comfort in relationships of importance, overall comfort, and how often participants have talked, or had contact those people or objects in the fast few days.

Access to information provided by respondents to these questionnaires will be restricted to those directly involved in conducting the study. All participants’ identity will be coded to protect privacy and confidentiality. Participants will not be directly identified in any report of this study’s findings.

On the next page, please indicate your willingness to allow me to approach and recruit participants who are patients under your care by marking the appropriate box below and signing where indicated. Return the signed page to me using the envelope provided with this letter; retain the first portion for your reference. If you have any questions or concerns regarding the conduct of this study, please contact me or my advisor, Patricia Higgins, PhD, using the information provided on page 1 of this document.

Thank you in advance for your consideration of this project.

Sincerely,

_Debra Lee, BSN, PhDc_

(330) 701-7845
email: dao5@cwru.edu
I give permission for Debra Lee to recruit and enroll study participants who are currently patients under my care at the Specialty Hospital at University Hospitals Extended Care Campus, in Chardon, Ohio. She may approach all my patients unless I communicate otherwise.

I want to be consulted on a case-by-case basis regarding my patients’ participation.

I do not give permission for Debra Lee to recruit and enroll study participants who are currently patients under my care at the Specialty Hospital at University Hospitals Extended Care Campus, in Chardon, Ohio.

Printed name

Signature             Date
Appendix M: Algorithm for consent of a patient receiving mechanical ventilation

Step 1: Patient meets inclusion criteria?
- Yes
- No → Stop

Step 2: Patient given brief explanation. Interested?
- Yes
- No → Stop

Step 3: Patient able to state name and age as requested?
- Yes
- No → Stop

Step 4: Patient able to identify correct color of paper being held before them?
- Yes
- No → Stop

Step 5: Further explanation of study and consent document. Willing to consent?
- Yes
- No → Stop

Step 6: Enroll in study.

You are being asked to participate in a research study because you recently have been hospitalized in an Intensive Care Unit for more than six days. Please read this form and ask any questions that you may have before agreeing to be in the research.

Researchers at Case Western Reserve University, Frances Payne Bolton School of Nursing are conducting this study.

**Background Information**
The purpose of this study is to understand how people who have been critically ill for a long period view their relationships during their illness. This research also will explore how relationships may have a bearing on your comfort and physical functioning.

Approximately 45 people will participate in this study.

**Procedures**
If you agree to participate in this research, we will ask you to do the following things:

- Complete two paper-and-pencil questionnaires about your relationships and your feelings of comfort.

- Complete a test that measures your physical and mental abilities. This is the Functional Independence Measure, the same test that Physical Therapists at this facility use each week to evaluate your progress.

Participation will require two sessions, one today and a second, follow-up session in about one month. Each session will last about one hour. The researcher will help you complete all tests. Today, we will complete all the tests here in your room. In one month, the tests will be repeated; at that time, you and the researcher will determine the best place to meet to conduct the second session of testing.

**Risks to Being in the Study**
There is a small chance that you may experience some emotional discomfort while answering the questionnaires. If you do experience emotional discomfort, you may take a break from answering the questions or choose to permanently stop answering questions.
Benefits to Being in the Study
There is no direct benefit to you. The benefit of participation is the possibility of helping to improve our understanding of the importance of relationships during chronic critical illness.

Confidentiality of Research Information
There is a risk to participants of loss of privacy. The privacy of your research information will be protected as much as possible. In addition to conducting all tests in a private location, the researcher will code your name and personal information and keep it in a locked file cabinet that only the researcher can access. In addition, the researcher will create passwords for any electronic information generated; the researcher will be the only person who will know these passwords.

Compensation
No compensation will be provided to you as a participant.

Costs to participants
There will be no cost to you as a participant in this study.

Alternatives to participation
You may choose not to participate. If you choose not to participate, but want to discuss your relationships with another professional (staff, administrator, clergy, for example), the researcher will inform the staff of your request so that arrangements can be made for you.

Privacy of Protected Health Information
The Health Insurance Portability & Accountability Act (HIPAA) is a Federal law that helps to protect the privacy of your health information and to whom this information may be shared within and outside of University Hospitals. This Authorization form is specifically for a research study entitled “The role of relationships during chronic critical illness” and will tell you what health information (called Protected Health Information or PHI) will be collected for this research study, who will see your PHI and in what ways they can use the information. In order for the Principal Investigator, Debra Lee, BSN, and the research study staff to collect and use your PHI, you must sign this authorization form. You will receive a copy of this signed Authorization for your records. If you do not sign this form, you may not join this study. Your decision to allow the use and disclosure of your PHI is voluntary and will have no impact on your treatment at University Hospitals. By signing this form, you are allowing the researchers for this study to use and disclose your PHI in the manner described below.

Generally the Principal Investigator and study staff at University Hospitals and Case Western Reserve University who are working on this research project will know that you are in a research study and will see and use your PHI. The researchers working on this study will collect the following PHI about you: information related to why you needed to be in an Intensive Care Unit and a Long Term Acute Care Hospital, medications you received, whether you were on a breathing machine (ventilator), and any other illnesses
you have. This PHI will be used to understand how people who have been critically ill for a long period view their relationships during their illness. This information will also be used to explore how relationships may have a bearing on your comfort and physical functioning. Your access to your PHI may be limited during the study to protect the study results.

Your PHI may also be shared with the following groups/persons associated with this research study or involved in the review of research: members of Ms. Lee’s dissertation committee (Dr. Patricia Higgins, Dr. Carol Musil, Dr. Mary Quinn-Griffin, and Dr. Christopher Burant); University Hospitals, including the Center for Clinical Research and the Law Department; Government representatives or Federal agencies, when required by law.

Your permission to use and disclose your PHI does not expire. However, you have the right to change your mind at any time and revoke your authorization. If you revoke your authorization, the researchers will continue to use the information that they previously collected, but they will not collect any additional information. Also, if you revoke your authorization you may no longer be able to participate in the research study. To revoke your permission, you must do so in writing by sending a letter to Patricia Higgins, RN, PhD at 10900 Euclid Avenue, Cleveland, Ohio, 44106; If you have a complaint or concerns about the privacy of your health information, you may also write to the UH Privacy Officer, Management Service Center, 3605 Warrensville Center, MSC 9105, Shaker Heights, OH 44122 or to the Federal Department of Health and Human Services (DHHS) at DHHS Regional Manager, Office of Civil Rights, US Department of Health and Human Services Government Center, JF Kennedy Federal Building, Room 1875, Boston, MA 02203. Complaints should be sent within 180 days of finding out about the problem.

The researchers and staff agree to protect your health information by using and disclosing it only as permitted by you in this Authorization and as directed by state and Federal law. University Hospitals is committed to protecting your confidentiality. Please understand that once your PHI has been disclosed to anyone outside of University Hospitals, there is a risk that your PHI may no longer be protected; however other Federal and State laws may provide continued protection of your information.

**Summary of your rights as a participant in a research study**

Your participation in this research study is voluntary. Refusing to participate will not alter your usual health care or involve any penalty or loss of benefits to which you are otherwise entitled.

If you decide to join the study, you can withdraw at any time and for any reason without penalty or loss of benefits. If information generated from this study is published or presented, your identity will not be revealed. In the event new information becomes available that may affect the risks or benefits associated with this study or your willingness to participate in it, you will be notified so that you can decide whether or not to continue participating. If you experience physical injury or illness as a result of
participating in this research study, medical care is available at University Hospitals Case Medical Center (UHCMC) or elsewhere; however, UHCMC has no plans to provide free care or compensation for lost wages.

**Disclosure of your study records**
Efforts will be made to keep the personal information in your research record private and confidential, but absolute confidentiality cannot be guaranteed. The University Hospitals Case Medical Center Institutional Review Board may review your study records. If your records are reviewed your identity could become known.

**Contact information**

[Some text redacted] has described to you what is going to be done, the risks, hazards, and benefits involved. The Principal Investigator, Debra Lee, can be contacted at 330-701-7845. You can also contact the Responsible Investigator, Dr. Patricia Higgins, at 216-368-8850. You can ask any questions you have now. If you have any questions, concerns or complaints about the study in the future, you may also contact them later.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; concerns regarding the study; research participant’s rights; research-related injury; or other human subject issues, please call the University Hospitals Case Medical Center’s Research Subject Rights phone line at (216) 983-5633 or write to: The Chief Medical Officer, The Center for Clinical Research, University Hospitals Case Medical Center, 11100 Euclid Avenue, Lakeside 1400, Cleveland, Ohio, 44106-7061.
**Signature**
Signing below indicates that you have been informed about the research study in which you voluntarily agree to participate; that you have asked any questions about the study that you may have; and that the information given to you has permitted you to make a fully informed and free decision about your participation in the study. By signing this consent form, you do not waive any legal rights, and the investigator(s) or sponsor(s) are not relieved of any liability they may have. A copy of this consent form will be provided to you.

_________________________________________ Date ____________________________
Signature of Participant                                                                 Printed Name of Participant

_________________________________________ Date ____________________________
Signature of Person Obtaining Consent                                                  Printed Name of Person Obtaining Consent

(Must be study investigator or individual who has been designated in the Checklist to obtain consent.)

_________________________________________ Date ____________________________
Signature of Principal Investigator                                                    Printed Name of Principal Investigator
Appendix O: Baseline Sociograms of SNA Participants 3 through 6

SNA Participant #3: Secondary participant responding was Fiancé.

SNA Participant #4: Secondary Participants who responded were Spouse, Sister
SNA Participant #5: Secondary Participant responding was Spouse

SNA Participant #6: No Secondary Participants responding.
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