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LOYOLA UNIVERSITY CHICAGO

IT IS ALWAYS THE MONKEY ON MY BACK: THE DIAGNOSIS OF CIRRHOSIS

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN NURSING

BY

MARY TIBERG

CHICAGO, IL

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ABSTRACT

A significant current challenge in health care today is meeting the needs of a population that has chronic disease, especially for those that have a health condition with a life threatening long -term outcome (Falkenstern, et al., 2005). In these health illness transitions, when there are no secure expectations, there are the additional burdens of enduring emotional unease, facing the closing stages of physical stamina, and confronting an indeterminate future. The objective of this study was to explore and describe the experience of those individuals who have been diagnosed with cirrhosis, which marks the beginning of end stage liver disease (Ebell, 2006). The goal of this research was to develop a more complete description of the phenomenon and process that an individual undergoes during this specific transition point in chronic liver disease and illness. This area of research has not yet been investigated. The research proposal for this dissertation, is presented, followed by a comprehensive literature review and the research question that is proposed for this study. These chapters are followed by the study methodology, which utilized grounded theory to discover the basic social process that an individual undergoes after being diagnosed with cirrhosis and living life with a threatening chronic disease and illness trajectory. The result of this study is a linear process that included twelve conceptual categories and a core category, that had a central relation to all other categories. This substantive theory is compared to other theoretical and conceptual work, along with the identification of the unique findings from this research. This dissertation is concluded with a discussion of the strengths and limitations of this work along, with recommendations for future application in nursing research, practice,

administration, and education. These implications include testing of the theory, tailoring care to meet the needs of this patient population, teaching the assessment and critical thinking skills that are needed to target nursing care, and the nursing resources that are necessary to care for this patient population.

CHAPTER 1

INTRODUCTION

Medical and nursing advances, along with healthier life styles have increased life expectancy and resulted in a significant number of individuals who experience chronic disease (Falkenstern, et al., 2005). It is estimated that by 2030 more than 20% of the population will be over 80 years old with approximately 45% of these individuals having a chronic disease, and most will have multiple conditions (Diamond, 2009; Douglas et al, 2007). Chronic disease is defined as an illness that is prolonged, does not resolve spontaneously and is almost never cured (Centers for Disease Control, 2003). Lasting illness is a profoundly troublesome experience, because everyday routines and the supposition's underlying one's continued way of life are no longer predictable or controllable (Lee & Poole, 2005).

Cirrhosis is the gravest form of liver disease and can be caused by any number of liver disease diagnoses. It is the final result of liver injury where scarring replaces normal tissue and liver function becomes compromised (Ebell, 2006; Neff, Duncan & Schiff, 2011). Currently, the diagnosis of cirrhosis is the 12th leading cause of death in the United States, and 4th in the age group of 45-54. The prevalence of cirrhosis in older adults is expected to increase over the next 20 years, in part due to the increased incidence of nonalcoholic fatty liver and the aging of those infected with Hepatitis C, making the diagnosis of cirrhosis a major public health concern (Neff, Duncan & Schiff, 2011; Rakoski et al., 2012; Tsochatzis, Bosch, & Burroughs, 2012).

Presently, the diagnosis of cirrhosis accounts for close to a half million hospitalizations annually, with more than 50% of those patients succumbing to their illness during that initial admission (Lynn, 2008; Rakoski, et al., 2012). For those individuals requiring an ICU admission, the probability of death during that hospital stay increases to 67% (Zimmerman et al., 1996). Nearly 20% of those that survive the acute inpatient admission will go on to require further hospitalizations within 30 days. Close to 75% of that population will experience continued hospital admissions in the ensuing two years at a rate of twice that of age-matched individuals without cirrhosis (Rakoski et al., 2012).

The overall costs associated with the diagnosis of cirrhosis embodies a significant economic burden, with the national cost of treatment in 2008 ranging from \$14 million to \$2 billion annually, depending on disease etiology (Neff, Duncan, & Schiff, 2011). In addition to formal care, individuals diagnosed with cirrhosis receive more than twice the number of hours of informal care, resulting in an additional cost of approximately \$5,000 per year, per individual (Rakoski et al., 2012).

Cirrhosis is the end result of chronic liver disorders, where normal liver tissue is replaced with fibrotic scar tissue (Neff, Duncan, & Schiff, 2011). The initial diagnosis of cirrhosis is a defining moment in patients with chronic liver disease (CLD). It signals a turning point in health concern, shifting the focus of patient care to prolonging physiological stability and for some, preparation for a liver transplant (Jarrett, 2009; Tsochatzis, Bosch, & Burroughs, 2012). Patients with cirrhosis encounter a progressively declining clinical course, a deterioration in physical condition, and complications that can be debilitating (Rakoski et al., 2012; Singh et al., 1997). With this diagnosis and change in physical condition, those diagnosed with CLD are forced into

transitioning from a stable point in illness to one that may be marked by a closed future and the loss of a familiar sense of self. Those individuals diagnosed with CLD must now incorporate a significant illness event into their life, with no clear linear path (Hattar-Pollara, 2010; Skaggs & Baron, 2005).

Chronic illness that results in an ominous diagnosis involves certain angst and difficulty for an individual (Thorne & Patterson, 2000). Particular diagnoses carry more powerful statements for individuals than others (Ekwall, Ternstedt, & Sorbe, 2007). These specific experiences have important categorical differences (Kralik, 2002; Thorne & Paterson, 2000). Chronic illnesses that are complex and involve the loss of personal control are determined to be more difficult transition experiences (Hatter-Pollara, 2010; Kralik, 2002; Schumacher & Meleis, 1994). These incidences signify a loss versus a gain, involve a great degree of strain and anxiety, and often occur suddenly with a time interval of uncertainty or permanency (Schlossberg, 1981). These complex chronic disease diagnoses are in contrast to situations where one perceives less of a loss, experiences a negligible difference between the pre and post transition environment, and benefits from both personal and situational support which affords the individual a less taxing situation (Brammer & Abrego, 1981). Situations that typify these health illness transitions include those that are straightforward and uncomplicated such as those that may only require a simple medication regime to rectify, or those where an individual is more in control to affect a positive outcome.

The experience of a serious chronic illness is an ongoing, continually changing event for an individual (Kralik, 2002). Cirrhosis and liver disease progression does not happen at a stable and steady rate in those diagnosed. Rather, it occurs at an inconsistent, variable, and erratic pace

(Gordon, et al., 2012). This depiction of an ever-changing and unpredictable disease course can preclude coping processes, which require both a cognitive and emotional appraisal of a situation (Folkman & Moskowitz, 2004). One's journey on this uncharted path is further complicated by recurrent dealings associated with end stage liver disease that escalate with time and diminish an individual's physical reserves. These events include a continual and steady physical and cognitive decline. End stage liver disease is often marked by encephalopathy, fluid overload as with ascites, and edema and hemorrhage with variceal bleeding (Rakoski et al., 2012). One faces a disease condition where they may not have yet learned to cope, or believe that they are in a situation that is beyond their control (Aujoulat, Luminet, & Deccache, 2007).

Chronic health-illness transitions are more than a life event. They are markers that require an intense process of personal change. Most of these changes are associated with hardship, an uncertain future, and apprehension. Each of these situations begins with an ending of health as one has known it. It is this ending, where one endures a compulsory disruption, that is most threatening for the individual (Bridges, 1980; Chick & Meleis, 1986; Gould, 1981; Kralik, Visenten, & Van Loon, 2006). One is being deprived of anticipated normal expectations (Stanton, Revenson, & Tennen, 2007). These events are demanding and complex for an individual because they not only incorporate physical symptoms, but a human response to those symptoms, which requires a change in assumptions or behaviors (Brammer & Abrego, 1981; Morse & Johnson, 1991). These changes are disquieting and contribute to a negative psychological state since there is not only a perceived loss of control, but of one's life being in jeopardy (Kralik, 2002; Morse, 1997).

The consequence of a diagnosis that is incapacitating, permanent, and ambiguous can

impede health-seeking behaviors. In those cases, the individual loses sight of a course of action that would affect more positive outcomes (Chick & Meleis, 1986). Diagnoses that carry a high level of uncertainty are particularly disturbing and worrisome for an individual. With ambiguity, there is insecurity and one can falter in matters of self-care, physical endurance, and psychological stamina (Morse, 1997). These individuals may be falsely perceived as non-compliant due to the insensitivity and inattentiveness of providers who fail to appreciate the magnitude of the experience for the individual (Kralik, 2002).

The meaning that one ascribes to a significant health-illness transition affects that individual's response to the situation. Meaning is equated with the subjective appraisal of the event and the evaluation of its likely effect. It is a construct that is fundamental in two life orders. Meaning influences one's sense of place and direction in the world. It also sways an individual's perception about a particular situation (Skaggs & Barron, 2005). The uniqueness of one's response to an event is attributed to the meaning that one has attached to that occurrence (Sundin & Fahy, 2008)

Major health-illness transitions that are exceedingly complex challenge the human capacity to endure and manage the event within their individual lives. This complicated process involves changes in behavior, relationships, and perspective (Schlossberg, 1981). In addition to an altered present, one undergoes the realization of an indistinct future (Morse, 1997).

Expectation is an additional subjective phenomenon and it is influenced by previous experience. This positions the individual in the situation with a certain frame of reference. When one knows what to expect, the stress associated with the event may be lessened (Davies, 2005; Schumacher & Meleis, 1994). In grave health illness transitions, with variable trajectories of

advanced complexity and impediment, one is not afforded this facilitating occurrence (Stanton, Revenson, & Tennen, 2007).

The demands of illness and related illness events touch individuals both physically and emotionally (Woods et al., 1993). These individuals work to maintain a public identity and execute social roles while simultaneously being burdened with a personal self that is unstable. It is this private self that is important to health care providers because it is in honoring this experience that we develop the basis for a perceptive and discerning client focused response (Morse, 1997; Telford, Kralik, & Koch, 2006).

As health care professionals confront the needs of a population that has chronic disease, especially for those that have a menacing health condition with long term and looming outcomes, it is essential to appreciate the experience that patients encounter in those serious health situations. In health-illness transitions, where there is a slow and subtle loss of control over well being, as well as an immense difference in disease progression, a valid challenge is presented to understand those human circumstances (Stanton, Revenson, & Tennan, 2007). Nursing, as a scientific discipline, is directed to investigate human experiences with illness. Moreover, nurses are charged with understanding the phenomenon associated with the emotional response and meaning that one ascribes to those events that encircle poor health (ANA, 2003). It is with an enhanced understanding of these conditions that the intangible becomes more objective. As health care providers, we can develop a more insightful and precise perspective for an individual's personal struggles with a clinical event that is long term, debilitating, and progressive.

In providing health care to those with chronic disease and illness there are two central

goals. These are to support both longevity and the quality of an individual's life for the years that one lives on with the disease and illness course (Kaplan, 1990). In advancing knowledge about the human experience with a health-illness condition that has a foreboding outcome, we can develop a deeper sensitivity and appreciation of what one endures when there is a change in one's physical condition that is now associated with a serious diagnosis. We add clarity to that which is invisible (Thorne & Paterson, 2000). It is with an enhanced understanding of the unfamiliar that we are able to become more attentive and accommodating in designing approaches in patient care that allow for more success (Cody, 2006). When effective measures are implemented that support an individual in a poignant and grave health-illness transition, there can be an overall improvement in outlook, attitude, and general health (Madar & Bar-Tel, 2009; Thorne, 1999; Treloar & Rhodes, 2009).

In several noteworthy studies, researchers have investigated health-illness transitions in patients with debilitating chronic diseases, resulting in three major themes. These common themes are the significance of the loss, uncertainty, and the time that one needs for an internal re-identification in order to incorporate the event into their life (Ekwall, Ternstedt, & Sorbe, 2007; McEwen, 2007, Riegel & Dickersn, 2008; Robinson, et al., 1997; Shaul, 1997). Each of these investigators suggested further study in areas of long-term progressive chronic disease, where individuals are living through health-illness transitions that are incapacitating and involve the loss of a familiar sense of self. With the passing of what one holds dear there is the additional burden of the sentiment and emotion that one assigns to those situations (Storch, Rodney, & Starzomski, 2004).

To date there have been no studies conducted on the experience of individuals who

endure the diagnosis of cirrhosis and the consequence of this diagnosis. In the arena of end stage liver disease, this marks an important deficiency in knowledge for a patient population that needs every opportunity for an outcome that is constructive. Evidence of healthy transitions is measured by the individual's ability to move positively through a health-illness transition with mastery of new skills and the development of a fluid, but integrative identity (Meleis, 2007; Schumacher & Meleis, 1994). Markers that portray a positive transition include a reconstructed and valued sense of self, a restructuring of life routines, maintaining continuity in relationships, and being able to accept both gains and losses in the experience (Schumacher, Jones, & Meleis, 1999).

The goal of this study is to investigate the research question of what is the basic social process that individuals undergo to live with the diagnosis of cirrhosis. Knowledge gained from this study will contribute toward deliberate nursing approaches for those who have long-term troubling diagnoses, with unpromising outcomes.

Conclusion

The diagnosis of cirrhosis poses physiological, social, and emotional stressors that individuals need to cope with. It is a clinical event that corresponds to a considerable change in health surveillance, a substantial concern for the loss of physical reserve, and doubt for an individual's emotional resilience. In understanding the individual response to a chronic diagnosis that has a protracted and arduous journey, we as nurses, come closer to grasping the phenomenon of that particular chronic illness experience (Telford, Kralik, & Koch, 2006; Thorne & Paterson, 2000). It is with this comprehension and insight that we develop the ability to offer more to those in our care. Clinical knowledge that includes a thoughtful and considerate

appreciation of the individual response to an untoward diagnosis supports the profession of nursing in developing durable therapeutic relationships, which persuade positive patient outcomes (Carper, 1981). Nursing care that is specifically tailored and personalized in the face of demanding clinical situations espouses the basic tenets of the profession. These professional nursing actions include the attributes to execute an encompassing and inclusive assessment, the expertise to implement effective action, and the personal ability to engage in a compassionate and caring relationship.

CHAPTER 2

LITERATURE REVIEW

The literature review addressed in this section includes the investigation of two concepts related to the diagnosis of cirrhosis. These concepts are differentiated as chronic illness and transition. Research literature related to chronic illness is addressed initially. This research is introduced with the topics of chronic illness, the differentiation of chronic disease from chronic illness, the demands and strain of chronic illness, and concludes with cirrhosis as a chronic illness condition. The review is then followed by the research related to the concepts of the illness trajectory, uncertainty in chronic illness and suffering associated with chronic disease and illness. The final portion of this section addresses coping abilities and how these capabilities are influenced when one is diagnosed with a chronic disease and illness condition. This section is concluded with a summary statement, a conceptual map and the specific implications that warrant further nursing study in the area of chronic illness, specifically with a diagnosis of cirrhosis.

In the second section in the literature review, the focus is on the concept of transition and Meleis' middle range theory for nursing (Schumacher & Meleis, 1994). There are three major frameworks that influenced Meleis in her development of the theoretical framework of transitions. They include the ethnographic work of Van Gunnup (1960) on the rites of passage, Blumer's (1969) contribution on symbolic interaction, and the work of Bridges (1980) who delineated the key processes involved in major life transitions. Each of these works are reviewed

and aligned to Meleis' theoretical framework. This section is followed by a detailed portrayal of the domains of Meleis' middle range theory and the findings in nursing research where the model was tested in practice. This portion of the review includes both a critique and summary of those research findings.

The final section of this review aligns the concepts of chronic illness and transition with specific attention to the diagnosis of cirrhosis. This discussion addresses the gap in the current literature with respect to the experience of those individuals that endure this diagnosis. This section is followed by the specific research question suggested by the literature to be examined in this dissertation.

Chronic Illness

Improvement in public health initiatives and the lowering of diagnostic thresholds for common chronic conditions, such as hypertension and glucose control has resulted in chronic health conditions currently being within the ten most prevalent causes of death in Western nations (Hunt, Kreiner, & Brody, 2012; Leventhal, et al., 2008). The treatment of these conditions creates a significant financial burden, with the associated cost of care consuming well over half of the health care budgets in developed nations (Leventhal, et al., 2008). Chronic conditions become more common with advancing age, leaving older individuals being challenged with one, if not multiple, chronic health conditions (Loeb, et al., 2003). It is estimated that 88% of older adults in the United States have at least one chronic condition, with close to 70% of those individuals having two or more chronic conditions (Falkenstern, et al., 2005). Although current health care financing and delivery systems focus on acute care, 78% of

actual health care spending is spent on the treatment of chronic conditions, with a total financial burden of \$1.3 trillion dollars annually (Ge & Runyon, 2013).

While the future of chronic illness management remains indistinct, the driving forces of longevity, health care funding, and consumer expectation for comprehensive quality health services generate opportunities for inquiry. Chronic conditions require long term management with a shifting in the course of care that is altered with both change in illness status and one's response to those changes (Corbin, 1993). Research in the areas of chronic disease and illness is particularly important for the profession of nursing. Specifically, deepened sensitivity to the struggles of those that are chronically ill can actualize exclusive care practices, which have the capability to influence patient outcomes (Jamison, 1998).

The Distinction of Chronic Illness from Disease

Chronic illness is differentiated from disease. Disease is defined as an undesirable physiological event (Conrad, 1990). In contrast, illness is depicted as a profoundly psychological process that rests on the experience with the physiological course and the perceptions and behaviors that ensue with that experience (Stanton, Revenson, & Tennen, 2007; Thorne & Patterson, 2000). Illness is the experience of disease (Woods, et al., 1993). The severity of a chronic disease impacts individuals' response to their diagnosis. Those with less severe and asymptomatic diagnoses, who have the advantage of deliberate action offering control, realize less of a disturbing health event (Leventhal, Leventhal, & Breland, 2011). Examples of these situations include diagnoses of hypertension, dyslipidemia, glucose intolerance, or marginal elevation in body mass index.

These less disturbing diagnoses are opposed to the experience of those who have a diagnosis that has an unremitting course and presents a serious threat to one's health status. This illness experience shatters a present reality and slowly erodes a prior identity (Mishel, 1990). These circumstances would comprise diagnoses such as cancer, systemic autoimmune disorders, chronic renal disease, and cirrhosis. With these conditions, the individual is challenged some way, whether by sporadic disruption in a steady state of being or by having to endure a disease progression that includes a persistent decline in health (Breen, 2002; Loeb, et al., 2003). One is forced into attending to the illness (Paterson, 2001). The psychological consequences of chronic illness pose questions for health care providers on the implications of a threatening health situation where there is a demanding and difficult health-illness transition (Hamburg & Adams, 1967; Stanton, Revenson, & Tennen, 2007).

It has been proposed that the onset of disease diagnosis and the cumulative effects of health loss are significant issues for those who are afflicted with a serious chronic disease. There is the hardship and strain of illness along with an uninvited instability and disorder that one has to integrate into their life. The personal burden and tension of disease and illness is addressed in the following section with the research works of Woods, et al., (1993) and Michael, (1996).

The Demands and Strain of Chronic Illness

Research in chronic illness maintains that there are common experiences across disease states. A construct that accounts for the collective experience of those afflicted with chronic illness is identified as the "tasks of illness" (Woods, et al., 1993, p. 11). This orientation includes the effort to manage disease, control symptoms, manage uncertainty, and normalize life. These points of reference provide an understanding of general experiences to a variety of chronic

illnesses. However, what this point of reference does not accommodate, is to pair the unique response to chronic illness with the shared human phenomenon. In order to expand work on the individual experience and response to chronic illness, Woods, et al., (1993), conducted further research to develop the concept of the demands of illness.

Woods et al., (1993) differentiated the concept of the demands of illness from illness related events. The variables related to the demands of illness were identified as adversity, apprehension, concerns, problems, or tensions that were associated with disease itself. The demands of illness, although considered arduous may also be appraised as opportunities for personal growth. Their research was designed to assess construct validity with the hypothesized relationships between the Demands of Illness Inventory developed by Haberman, et al., (1990) and measures of individual, dyadic and family adaption.

The focus of this scholarly work was to assess the relationship between certain types of illness demands experienced by women and the effect of these demands on individual, marriage and family adaption. The three domains of illness demands were identified as the disease related demands of illness, personal disruption demands, and environmental transactions. The disease related demands include both the physical and psychological experiences that are direct result of the disease itself and would include the instances of pain, fatigue, and nausea. Personal disruption demands were the changes in normalcy that one encounters. Illness demands that were linked to environmental transactions were those events that occur in one's social environment and include the contest one may have in relationships with family, social networks, and health care providers. The hypotheses proposed that women with more direct disease demands, more

personal disruption, and more environmental transactions would report poorer individual and family adaption to the illness.

The study design centered around 125 participants with three cohorts of individuals who were diagnosed with breast cancer (n=58), diabetes (n=31) and fibrocystic breast changes (n=36). Those diagnosed with breast cancer were selected because they were facing a life-threatening diagnoses and those with diabetes were chosen because they dealing with a life-long daily treatment routine. Participants were selected who had been diagnosed for at least two years, as the emphasis of this study was on the experience of those living with a chronic illness. Those women with fibrocystic breast changes were selected as the comparison group, where they were not facing a life-threatening situation or an ongoing treatment regime. Participants were administered the Demands of Illness Inventory (Haberman, et al., 1990) along with measures of adaption utilizing the Center for Epidemiologic Depression scale (Radloff, 1977) and adjustment being assessed with the Spanier Dyadic Adjustment scale (Spanier, 1976). Family cohesion and functioning were measured with two instruments. Those measurement tools were the Family Adaptability and Cohesion (FACES) (Olson, Portner, & Bell, 1982) and the Adaptability, Partnership, Growth, Affection and Resolve (APGAR) (Smilkstein, 1978).

The results of this research showed evidence of support for the hypothesis that demands of illness directly affect individual, marital, and family function and adaption. Specifically, the researchers noted that the physiological effects of the disease or disease demands were positively correlated with depression ($r = .203$) and poorer individual adaption ($r = .201$). Illness demands associated with personal disruption, such as the need to re-evaluate priorities and the value of life were correlated to individual, dyadic, and family functioning. Those reporting the most demands

in this area reported more depression ($r = .203$), poorer marital adjustment ($r = .287$), and lower satisfaction with family ($r = -.391$). Demands related to environmental transactions with family functioning, as in the need to shift or change roles were correlated to dyadic and family adaption. Again, those who were experiencing the greatest encumbrance experienced significantly poorer adjustment in personal relationships ($r = -.102$) and family adaption ($r = -.277$). The authors purport that the findings from this research support that the direct effects of illness produce demands with the disease course that impose consequences with individual, dyadic and family adaption.

The findings in this study by Woods, et al. (1993) report a positive relationship between the Demands of Illness Inventory and indicators of individual, dyadic and family adaption. However, the magnitude of these relationships was low. These findings do not support convincing evidence of a strong relationship between variables.

The sample size in this study had cohorts of unequal size, with the breast cancer cohort being nearly twice the size of the other two cohorts and without group differences being reported. With group differences or similarities not being reported, one could question dissimilarity in groups affecting outcome measures. Additionally, the sample selected for this study was with women who had a diagnosis of disease for two years. Those who have been diagnosed for this time period may have already made adjustments to their illnesses, leaving this sample producing less variation on score measures and possibly accounting for the low correlations reported.

The researchers did report novel and relevant findings in this study with those women who had lived with their disease for at least two years. Those individuals showed less of a

relationship between indexes of adaption, illness attributions, or disease symptoms. These findings do suggest that aspects of illness and disease produce greater personal disorder in the early and late stages of the disease, than during the intermediate phase of the illness experience. The authors suggested that this finding supports future research work, where it has been suggested that the investigation of the individual effects of the demands of illness in the early post diagnostic phase would contribute to a more complete care framework. In understanding the distress and difficulty associated with the onset of a diagnosis that is associated with chronic illness, health care providers would have enhanced abilities to assess anxiety, understand stressors and implement care strategies that influence better patient paths (Corbin & Strauss, 1991; Woods, et al., 1993).

In a phenomenological inquiry conducted by Michael (1996), the interest in understanding the experience of those afflicted with chronic disease and the strain of integrating illness into their lives was investigated. The research question that guided this inquiry was to ask: what is the lived experience of integrating chronic illness in to one's life. The sample size consisted of 17 chronically ill adults who ranged in age from 21-75 and included 3 men and 14 women with illness duration ranging from 5-48 years. All participants were willing to verbalize how they lived with chronic illness. The sample included those with chronic diseases of diabetes mellitus, coronary artery disease, rheumatoid arthritis, chronic obstructive pulmonary disease, and asthma.

Four major themes emerged, which included loss, fluctuating emotions, making changes, and gaining control of an altered life direction. Incorporating chronic illness into one's life was found to be a forceful, multi-faceted, multi-part experience for participants. Loss was a central

matter to all, with the ability to participate in life as desired, being denied. Individuals' described the emotional mayhem with chronic illness. At times one is "thankful for what they have, only to be jealous the next moment for what they don't have" (Michael, 1996, p. 258). Change is a constant human challenge. However, with chronic illness, changes are involuntary, unexpected, and uninvited. These changes replace old routines with continual prompts of the effect of illness on their life. The cumulative effects of loss and unwanted changes modify a life direction, leaving one with less control and direction (Michael, 1996).

A troubling finding in this study was that health care providers were seen as contributing to an individual's loss. The perception of these study participants was that they were not seen as more than their illness. The disease diagnosis was what was foremost, leaving a diminished and detracted understanding of the individual experience. To be able to put forward strategies that offer an individual more capability, one must first develop the skill to create caring environments where patients and their experience will be understood and appreciated. Michael (1996) suggested that this potential lies in health care providers listening to what patients tell them that is significant for them during their illness experience. It is with this attention that health care providers will be able to create caring environments, where those in their care feel that we understand their illness experience with chronic disease (Michael, 1996).

Cirrhosis as a Chronic Illness Condition

Liver injury may be the result of infectious, autoimmune, vascular, hereditary, or chemical factors. Cirrhosis is the end stage of chronic damage to the liver, which can be caused by any one of these conditions. It is a diagnosis that indicates the final result of liver injury and is characterized by the formation of scar tissue, which results from the destruction of normal liver

parenchyma (Lefton, Rossa, & Cohen, 2009). As the progressive cascade of liver tissue destruction continues and liver function becomes more compromised, the individual holding the diagnosis of cirrhosis concedes to diminished mental, physical, and biochemical function (Ebell, 2006; Neff, Duncan, & Schiff, 2011). The diagnosis of cirrhosis indicates a central change in the focus of medical attention and physiological monitoring, the concern for the loss of physical stamina and reservations for an individual's emotional endurance. This point in the care of those with liver disease is where one transitions from a secure point in illness to one that is defined as end stage (Tsochatzis, Bosh, & Burroughs, 2012).

Cirrhosis is a diagnosis that is marked with ambiguity, a negative implication, and an illness trajectory that is inconsistent and contradictory (Jarrett, 2009). It is a protracted chronic condition that requires the individual to adjust physically, socially, and psychologically (Thorne, 1998). The process of scar tissue development in the liver is an asymptomatic, insidious, and a silent event for most individuals (Gordon, et al., 2012). This actuality of the absence of salient symptoms and an indistinguishable pattern of disease progression makes the diagnosis of cirrhosis a disquieting and disturbing experience, marked with uncertainty (Mishel, 1988; Ge & Runyon, 2013). It has been proposed that by developing a deeper understanding of the distress and difficulty associated with the onset of a diagnosis that is linked with long term detrimental and injurious effects, we enhance our ability to care for individuals and steer outcomes that are both constructive and beneficial (Corbin & Strauss, 1991; Gould, 1981; Woods, et al., 1993).

The diagnosis of a complex disease and the chronic illness experience places one in a situation where there is a negative trajectory with temporal uncertainty and continued suffering. These cumulative events negatively affect an individual's ability to implement problem focused

coping skills and can result in one being less capable of integrating the disease and illness into their life. When one is unable to engage in problem focused coping skills they are at risk for distress and tension. The concepts of the chronic illness trajectory, uncertainty in illness, quality of life, suffering, coping, and adjustment, and the related research to each of these concepts will be discussed in the following sections. This section is concluded with a conceptual map of these concepts for both chronic diseases in general and specifically for the diagnosis of cirrhosis. The following section addresses the chronic illness trajectory (Corbin & Strauss, 1991).

Chronic Illness Trajectory

Corbin & Strauss (1991) believed that the individual management of a chronic disease and illness condition encompasses more than the control of symptoms, learning to live with disability, and adjusting to the psychological changes that come with having to live with a permanent and irreversible condition. It includes all of this and more. In order to enhance understanding of the illness experience of those who are afflicted with chronic disease, and influence an approach in the nursing care of these individuals, they proposed a trajectory framework. The framework integrated existing literature on chronic conditions and provided nursing with a directional course in approaches to care. The trajectory framework holds two major premises. The first is the concept of trajectory, which is defined as an illness course that is uncertain and ever changing. The concept was inductively derived because it is merely understood retrospectively, with one only being able to manage a purely imminent appreciation of an individual's encounter.

The second key premise in the trajectory framework asserts that when the profession of nursing comprehends the context of the illness experience more completely, engaging behaviors

can be executed to influence a more positive patient outcome. These interventions are more inclusive than complex technical skills, and include acts of teaching, counseling and planning. When these interventions are effectively implemented, it is proposed that a better quality of life is shaped for those who are under nursing care. With an enriched comprehension of the illness experience, and the many and varied changes in condition that one undergoes, one further appreciates that interventions are not indeterminable. They are only durable for as long as a condition remains stable. Any changes in the illness trajectory carry with it new conditions that bring about effort and struggle for the individual (Corbin & Strauss, 1991).

A central assumption in the trajectory model is that the chronic illness experience can be shaped and managed over time, even if the physiologic disease course cannot be modified (Corbin, 1993). Although a disease path may take a particular negative course, it is in the nursing efforts of care and management of tentative conditions that persuade patient control, coping, and consequence with the illness experience (Robinson, et al., 1993). These purposeful and directed professional actions are intervening therapies that allow for something else for the individual (Schumacher & Meleis, 1994). This shaping process necessitates nursing to be an active agent in an individual's ability to respond to the dimensions of chronic illness, where the prevailing condition is sustained uncertainty. These shaping processes include the nursing actions of averting complications, implementing care regimes, responding to a health crisis, and supporting one to continue on with life and being, despite illness (Corbin, 1993; Walker, 1991).

Uncertainty about future events with any chronic illness is a central issue for anyone afflicted with a long term diagnosis. It is the cognitive state created when one is unable to accurately predict outcomes because sufficient information is lacking. Uncertainty is the

outcome of ambiguity, complexity, and the unpredictability of proceedings, which results in the individual being incapable of developing a cognitive schema for illness events (Mishel, 1988; Mishel, 1990). The following section addresses this concept in relation to chronic disease and illness. Three areas are addressed in this section. These topics include the differentiation of event and temporal uncertainty (Monat, Averill, and Lazarus, 1972), the theoretical and research work of uncertainty in nursing (Mishel, 1988; 1990) and the conceptual analysis of uncertainty conducted by Penrod (2001).

Temporal and Event Uncertainty

Monat, Averill, and Lazarus (1972) investigated an individual's stress response in two dissimilar, uncertain situations. These situations are labeled temporal uncertainty and event uncertainty. Temporal uncertainty refers to situations where one does not know when unavoidable harm will come. This is in contrast to event uncertainty, where the individual knows the timing of the occurrence of harm but the probability of the occurrence is less than certain. The researchers examined stress and anticipatory coping reactions in both of these uncertain situations by designing a quasi experimental study between two groups of randomly selected subjects.

The study was comprised of three groups. The control group received no intervention. The other two study groups consisted of 20 male subjects who underwent either temporal or event uncertainty in three trial situations. Temporal uncertainty was the condition of a 100% probability of a shock with a time unknown and an event uncertainty was the condition of a 50% probable shock at a known time. Physiological measures of affective arousal were measured by heart and respiratory rate and skin sweat level response. Coping was measured in two ways. The

first was subject recall of their experience and this was categorized as either vigilant type activities or avoidant like thoughts. Vigilant behaviors were described by the researchers as the cognitive thoughts that subjects described about the impending shock and avoidant behaviors were measured as subjects expressing thoughts of events unrelated to the experiment as in thinking about movies, songs or dates. The second method of assessing cognitive function during anticipatory stress was for subjects to rate on a 5 point scale the degree that they could remember their experiences during the three trial events.

Group differences were reported with those subjects experiencing event uncertainty having an elevated affective arousal with reported higher heart and respiratory rates and sweat skin responses than those subjects who underwent temporal uncertainty ($p < .001$ reported for all three measures). In the measures of patterns of coping with vigilant behaviors and recall, those subjects in the temporal uncertainty group reported a decreased amount of time on vigilant-like thoughts versus those in the event uncertainty group ($p < .001$). Subjects in the event uncertainty group reported progressively better recall of material throughout the trial than those subjects who were exposed to temporal uncertainty, with the timing of the shock being unknown ($p < .01$).

The findings of this study were interpreted as those persons who know that an aversive event will occur, even if it is uncertain, exhibit increased vigilance and arousal. This is in contrast to those subjects who experienced temporal uncertainty, with the timing of an unpleasant event being unknown. These individuals reported avoidant modes of coping and demonstrated lower levels of affective arousal. Monat, Averill, and Lazarus (1972) concluded from these findings that the condition of temporal uncertainty was more threatening for the individual and

this level of uncertainty lead to different modes of coping where study participants utilized avoidant thought behaviors and less direct action.

Mishel: Uncertainty in Illness

Diagnoses that carry a level of uncertainty are particularly difficult for an individual (Dewar & Morse, 1995). Uncertainty is a complex variable that is associated with events which are unpredictable. It is an individual judgment about an unstructured situation where one lacks a frame of reference to move forward (Mischel, 1981). This concept is considered a key antecedent to anxiety (Monat, Averill, & Lazarus, 1972).

In situations of uncertainty, one comprehends the goal of changing the present circumstances. What is deficient for the individual is the means to reach that goal. Those aspirations cannot be evaluated because one does not have sufficient information to appraise alternatives. One lacks the ability to understand options and there is an inability to predict outcomes (Mishel, 1988; Morse & Penrod, 1999). One exists in an emotional state, unable to move forward, select options or take action. Hope, which, has been defined as the probability of success and an inner conviction that a goal is obtainable, is lost for the individual in an uncertain circumstance (Frank-Stromberg, 1988; Morse & Penrod, 1999).

Mishel (1981) investigated this concept with the purpose of exploring uncertainty as a significant variable in an individual's experience with illness. Her initial work began in her doctoral dissertation with the development of a conceptual framework of uncertainty in illness (Mishel, 1980). The model was structured on the works of Moos (1977) and Lazarus & Folkman (1984). Moos (1977), was a behavioral theorist who classified four event categories in illness-treatment situations. The first category is the symptoms of the disease itself. The second event is

the management and treatment of the disease. The third event involves the technical environment and the final category includes unfamiliar routines. This last category focuses on the individual assessment of future independence.

When events are perceived to be uncertain, they are existent because either the nature of the stimulus has an unpredictable and random pattern of occurrence or that the individual has an incomplete context or frame of reference for the event. Illness events that are uncertain are appraised as threatening to individuals because of both the implausibility of the situation and an inability to grasp a secure future direction. One is incapable of employing direct action and information seeking behaviors, which can lessen the threat and promote coping modes (Lazarus & Folkman, 1984). It is proposed that the ambiguity factor holds the highest promise of threat to the individual because one is unable to consistently perceive harm, making coping abilities more difficult (Shaul, 1997).

Regardless of the source of uncertainty, when an event is judged as uncertain there are common experiences to all individuals. These include the dimensions of vagueness, lack of clarity, inconsistency, unpredictability, probability, multiple meanings, and lack of information. These dimensions hamper an individual's cognitive structure which then impedes decision making and behavioral responses (Mishel, 1981).

Based on this conceptualization, Mishel (1981) developed a measurement scale of uncertainty in illness based on a two factor structure of ambiguity and unpredictability. The Mishel Uncertainty in Illness Scale (MUIS) was initially developed as 54 item instrument scored on a five point Likert scale (Mishel, 1981). The tool underwent three validation studies. To establish construct validity evidence, the scale was initially tested with a sample that reflected a

situation where there was consensual agreement that uncertainty exists. The diagnostic phase of a disease would fit the conceptual definition of uncertainty where events are unclear and one has unfamiliar cues. Construct validity was tested in two groups of individuals, those with a determined diagnosis and those in a diagnostic work up situation. The hypothesis tested was that patients undergoing a rule out diagnosis will perceive more uncertainty than those with a determined diagnosis utilizing the MUIS tool. The results of those with a determined diagnosis versus those with undergoing evaluation procedures demonstrated expected results in t-test results with $p < .003$, which demonstrated support for the construct validity of the scale (Mishel, 1981).

Convergent validity is the measurement of validity by two independent measures for the same variable with results correlating (Nunnally & Bernstein, 1994). In the study conducted by Mishel (1981), the researcher studied two relationships. The first was the degree of stress experienced by hospitalized patients and perceived uncertainty. This was measured by the Hospital Events Scale and the MUIS tool. Results indicated that a patient's level of perceived uncertainty was positively related to hospital stress events ($r = .35$). The second relationship investigated was that uncertainty would be related to a lack of comprehension. This hypothesis was tested utilizing the MUIS tool and the Comprehension Interview Measure (Cassileth, 1980). The correlation between uncertainty and comprehension resulted in a predicted direction with higher levels of uncertainty correlating to a lower level of comprehension ($r = -.56$). This testing indicated initial support for convergent validity, with correlation of the concept of uncertainty in two distinct measures of the concept, which were hospital stress events and levels of comprehension.

Mishel (1981) continued validating the MUIS by testing of the relationships between the three main areas in her developing theory of uncertainty over the next four years in five clinical studies. The purpose of this work was to continue to explore the emerging areas of perceived uncertainty and coping, outcome criteria of uncertainty and antecedent conditions that produce uncertainty in various patient populations. The work would additionally provide empirical evidence for the development of her theoretical framework. Those research initiatives include the development of a pediatric instrument to evaluate the perception of uncertainty in a parent's concern with an ill child (Mishel, 1983), evaluating uncertainty in acute care patients with a major physiologic event (Mishel, 1984), investigating the psychological adjustment with newly diagnosed gynecological patients (Mishel, Hotsetetter, King, & Graham, 1984), determining the relationship between social support and uncertainty (Mishel & Braden, 1987), and the identification of the process that family members undergo when managing the unpredictability of loved ones who live through a solid organ transplant (Mishel & Murdaugh, 1987). These collective studies served as the basis for Mishel's theory development and will be reviewed in the following portion of this section.

Development of Mishel's Middle Range Theory of Uncertainty

Mishel (1983) investigated uncertainty and the experience of parents during their child's illness by developing a modified version of her original measurement scale which was specific to a pediatric population. The tool was administered to 237 study participants over a six month period with four factors emerging from the data as measures of uncertainty. Those factors were identified as ambiguity, lack of clarity, lack of information, and unpredictability. Correlation was determined between a parent's uncertainty and seriousness of illness ($r = .16$). Additional

correlations were measured and reported for ambiguity ($r = .28$), lack of information ($r = -.12$) and unpredictability ($r = .10$). These findings offer reserved correlations that the tool would provide a means to evaluate the perception of uncertainty in one person over the concern of another.

To examine the relationship between seriousness of illness, uncertainty, and stress, Mishel (1984), conducted an investigational study on 100 hospitalized individuals who had a medically related illness that involved a major physiological system. Participants were administered the Mishel Uncertainty in Illness Scale, as a measure of uncertainty and the Hospital Stress Rating Scale, as a measure of stress. Severity of illness was measured by primary diagnosis coding. The results of this study revealed that the level of perceived uncertainty was related to ratings of hospital stress ($r = .35$, $p < .001$), that when multiple aspects of illness and treatment were perceived as uncertain, they were viewed as stressful ($r = .19$, $p < .05$) and a high correlation was demonstrated between lack of information and uncertainty ($r = .51$, $p < .001$). Mishel (1984) concluded that patients with more serious illnesses had experienced added stress in the area of lack of information and the fear of being gravely ill.

The theorist suggested that it is the vagueness, lack of clarity, and an information deficiency about events that accounted for these results versus the event itself. Mishel (1984) defined this as promoting congruency, where the perception of uncertainty can be reduced by the generation of a cognitive structure based on the accurate description of sensations. She proposed that when the patient is enabled in developing this cognitive structure, they will be more able to accept the imminent experience, assess the meaning of the situation, and to get through the demand of the event (Mishel, 1984).

The four variables of uncertainty, optimism, adjustment, and seriousness of illness in women with a newly diagnosed gynecological cancer were investigated in a descriptive correlational study conducted by Mishel, Hostetter, King, and Graham (1984). In this study, 54 women who had a new diagnosis of gynecological cancer and not yet begun treatment were administered the Mishel Uncertainty in Illness Scale (MUIS) as a measure of uncertainty, the Beck Hopelessness Scale as a measure of optimism, and the Psychological Adjustment to Illness Scale as a measure of adjustment. Seriousness of illness was measured by a one item measure with a scale range of 1 to 10, which was the index measure for degree of control over physical function.

The results from this study demonstrated that younger patients rated their illness as more serious ($r = -.28, p < .04$), younger patients had more psychological distress ($r = -.39, p < .003$) and subjects with less education experienced more uncertainty in the area of the complexity of the procedures ($r = .30, p < .03$). Uncertainty had a negative association with optimism ($r = -.05$). The uncertainty factor of perceived complexity concerning treatment and negative future expectations were related ($r = -.31$), where it appears that when the treatment was perceived as difficult, then the future was evaluated as likely to be objectionable. Absence of information was associated with a decrease in motivation ($r = -.27$). The findings from this study supported proposing that uncertainty in the diagnostic event was not a preferred state. It was associated with a lack of optimism and motivation, poor future expectations, and a belief that events would not be favorable.

In order to address the specific function of social support and the impact on uncertainty, Mishel and Braden (1987) designed a correlational descriptive study to determine the

relationship between these variables. The sample consisted of 44 women who again had a first time diagnosis of gynecological cancer and had not begun a treatment protocol. These women were studied during the phases of diagnosis and testing, the treatment phase, and the adjustment phase, which was determined to be 8 months after treatment. Three measurement tools were utilized. Social support was measured by the Norbeck Social Support Questionnaire, uncertainty was measured with the Mishel Uncertainty in Illness Scale, and psychological adjustment was evaluated by the Psychological Adjustment to Illness Scale.

The research findings from this study indicated uncertainty was related to social support functions of affirmation ($r = -.33$), affect ($r = -.29$) and aid ($r = -.26$) in the diagnosis phase. The researchers concluded from these findings that women reported more emotional expression in their relationships when others had deference for their ideas and opinions. These women had less ambiguity about the state of their illness and a greater source of information.

During the treatment phase, the functions of social support were associated with uncertainty in the area of complexity concerning treatment ($r = -.39$). The social support functions that accounted for this relationship were affect ($r = -.37$) and affirmation ($r = -.41$) which the researchers reported as being highly correlated with complexity. In the stabilization phase, there was an association between social support functions and uncertainty ($r = -.28$) and social support functions and unpredictability ($r = -.35$). The researchers concluded that these findings supported that when women had social resources which offered either figurative or actual assistance, they viewed the course of their illness or its outcome as more predictable.

The results of this study added support for the functions of social support and that this support is differentiated over time. In the diagnosis phase, social support functions provided

affirmation which allows one to have a clearer view of the circumstances. During the treatment phase, social support functions to assist one in reducing the perception of a lack of control and to encourage attention to positive aspects of the given situation. In the stabilization phase, social support functions to provide the individual with a more complete range of social assets that include the assurances of a steadiness in relationships, a reduction in feelings of helplessness and the ability to diminish the unpredictability of the outcome by knowing, that although the future is unknown, there are close others to help (Mishel & Braden, 1987).

In order to identify the processes that family members use to manage the uncertainty associated with a loved one needing a heart transplant, Mishel and Murdaugh (1987), conducted a qualitative study utilizing grounded theory methodology. The sample consisted of 20 family members of patients who underwent a heart transplant. Data collection took place over 2 ½ years with a core variable and three themes emerging from the data analysis. The core variable was identified as redesigning the dream, which described how family members gradually revised their beliefs about organ transplant and developed positions to confront the challenge of living with sustained uncertainty. The three themes that emerged were categorized as immersion, passage, and negotiation.

Immersion was identified as a series of behaviors by which the family member directs all efforts toward maintaining life and comfort for the patient. The feature of uncertainty at this point is that of organ availability. The time interval for the organ procurement and receipt is unknown and the family member can do nothing to influence that occurrence. The only manageable option for the family member is to maintain the patient's condition and evade deterioration and death. The partner frees themselves of all non-essential obligations and shifts

energy and attentiveness to the patient. Their life is on hold with little involvement in any other life activities.

As one undergoes a heart transplant, they move from imminent death to a second chance at life. The partner, at this time moves from immersion to independence. They are now able to have an emotional release of the stressful events related to the pre-donor period, which was a time of capriciousness and instability. There is a belief that the ordinary will return. However, this passage phase continues to be marked with uncertainty when initial post op complications can fracture and erode the dream that there will be a future return of normal. One becomes aware of the necessity to re-define normal. Success in this phase is defined as having the ability to view the future in a positive light.

The negotiation stage begins with the partner speaking of living with continual uncertainty. The partner begins to comprehend that a new life needs to be structured to include one's vulnerability, the relinquishing of former mutual life goals and the potential that one will continue in life without their loved one. One adapts to a new view of life and a new reality. Modifying behaviors that help to achieve this end include extreme role changes and long lasting amendments to expectations. This negotiation phase is a long term and gradual process with patients and partners reporting role changes continuing one year after transplant.

These collective studies served as the basis for Mishel (1988) to develop a middle range theory of uncertainty in illness with the appreciation that there needed to be continued research work on perceived uncertainty and coping, uncertainty and outcome criteria, antecedent conditions eliciting uncertainty, and for the concept to be studied across a broad range of

populations (Mishel, 1983; Mishel, 1984; Mishel & Braden, 1987; Mishel, Hostetter, King, & Graham, 1984; Mishel & Murdaugh, 1987).

Mishel's Middle Range Theory on Uncertainty

Mishel's middle range theory is organized around three major themes, which include antecedent factors of uncertainty, the process of uncertainty appraisal, and coping with uncertainty. Antecedent factors are those events that precede and contribute to an awareness of uncertainty. They include a symptom pattern, an event familiarity, and event congruence (Mishel, 1988).

Symptom pattern refers to the presentation of symptoms which have a sufficient consistency to be perceived as having a pattern. Symptom patterns which are not discernable, as in some chronic illnesses, would present with more uncertainty for the individual. Event familiarity is the habitual or repetitive nature of the structure of the environment. When treatment regimes are routine and constant there are lower levels of uncertainty. This is in contrast to illness experiences where unique and unfamiliar events prevail. Event congruence is the consistency between individual expectation and the reality of what one is experiencing with the illness related events. Those who endure health events that do not hold this component of event congruence would be in positions of high uncertainty. One's expectations are eradicated.

The antecedent factors of symptom pattern, event familiarity, and event congruence are influenced by two conditions. These are cognitive capacity and structured providers. Cognitive capacity refers to the information processing capabilities of the individual. The most susceptible processing abilities are attention resources, with physical disease being a powerful detractor in

the amount of attention that one is capable of devoting to a cognitive task. This issue influences and impairs problem solving abilities (Mishel, 1988).

Mishel (1988) identified three ordered sources, which she classified as structured providers, that influence the condition of uncertainty for the individual. They include education, social support, and credible authority. Education is considered to have both a direct and indirect relationship to uncertainty. A direct educational influence is demonstrated in those with less education having higher levels of uncertainty both in the perception of the event and in understanding the circumstances. Those with higher levels of education required less time to construct the meaning of the event and experience uncertainty for shorter time intervals. Education indirectly influenced uncertainty when knowledge gives structure and a base for the event, thus providing the individual with context, significance and implication regarding the experience.

Social support averts uncertainty by supplying feedback on the meaning of the event. One has assistance in interpreting the implication of the events. In addition, social support allows for a network of relationships where one can depend on another and their experiences to assist in handling threatening events (Mishel, 1988). Credible authority refers to the degree of trust and confidence that patients have in health care providers. This relationship with health care providers is considered to be a key means in the prevention of uncertainty in illness. The faith that one has in their relationship with a health care provider enhances predictability and supports one in interpreting their illness experiences.

The experience of uncertainty is a neutral occurrence until there is an individual assessment of the situation. Mishel (1988) contends that there are two major processes that an

individual employs in the assessment of uncertain situations. These processes are identified as inference and illusion. Inference refers to the individual's ability to use past experience and general knowledge to evaluate the uncertain situation and exert some direct rule. In those illness situations that are ambiguous and lack a predictable course, one would be unable to draw on past experience or knowledge to judge the situation, leaving one less able to exert control.

Illusion refers to the beliefs formed out of uncertainty. These beliefs generally take a positive position and are viewed with emphasis on favorable aspects (Taylor, 1983). It has been suggested that the maintenance of illusion is protective to individuals who are in the initial stages of a threatening situation and when one must accept that which is difficult (Lazarus, 1991; Lazarus & Folkman, 1984).

The characterizations of inference and illusion are closely associated with the earlier work of Monat, Averill, and Lazarus (1972) in which the researchers characterized event and temporal uncertainty. With temporal uncertainty, when harmful events are unpredictable, the individual would be incapable of exercising any significant degree of control or power with the circumstances. This individual would have a continued assessment of danger or threat with the situation. Mishel (1988) asserted that this individual experience places one at high risk for an adverse outcome of emotional distress. In comparison, although event uncertainty bears the potential for an objectionable experience, when one knows the timing of the event, there is the ability for one to assert personal control and draw on familiarity and knowledge from the previous experience. This situation would permit the individual a less uncertain situation and allow for reduced emotional difficulty.

Illusion is the assurance that one forms with the appraisal of the uncertain situation. It is when the individual judges the event to be an opportunity and hope is maintained (Mishel, 1988). In these assessed circumstances, one is more adept to employ directed coping actions with the end result of adaption being a more likely outcome. This finding was demonstrated in the study conducted by Monat, Averill, and Lazarus (1972). In individuals who experienced temporal uncertainty, with events being erratic and variable, they were less able to employ the coping activities of direct action, information seeking, or vigilance, leaving one vulnerable to difficulty and distress.

Without the ability to utilize direct action as a coping mechanism one encounters less capability to counter a threatening situation and is prone to exhibiting emotional reactions to stress (Mishel, 1980). What remains indeterminate are the types of events that foster vigilance or avoidance behaviors or how these coping methods bear up to the persistent input of negative health events that are a part of a chronic illness that has a tentative trajectory (Corbin & Strauss, 1991; Robinson, et al., 1993).

Based on the individual's assessment, the uncertain situation may be regarded as either a danger or an opportunity (Mishel, 1988). When a situation is appraised as dangerous, coping mechanisms are directed at reducing uncertainty with two coping methods. These are identified as mobilizing activities and affect management. Mobilizing activities include direct action, vigilance, and information seeking. These actions are problem focused and are employed when the situation is assessed as manageable. Affect management holds the actions of emotionally focused strategies and are associated with the acts of faith, disengagement, avoidance, wishful thinking, and selective ignoring. These strategies are aptly utilized when the event producing

uncertainty cannot be altered and they assist one in managing the emotional provocation associated with the occurrence (Mast, 1995; Mishel, 1988).

Uncertain situations that are considered as an opportunity are a result of an individual's appraisal and the illusionary structure of a more positive outcome. When uncertainty can be viewed as an opportunity, Mishel (1988) asserted that hope is possible and that it can be an ongoing active state. This contention is inconsistent with later evidence and work that maintained hope is paralyzed in uncertain situations (Frank-Stromberg, 1988; Morse & Penrod, 1999). These dissimilar assertions may be explained by further theoretical work and refinement of the concept (Penrod, 2001).

When coping strategies are effective, Mishel (1988) upholds that adaption will occur. She defined adaption as the biopsychosocial behavior that occurs within a person's individually defined normal and customary behavior. It is when the individual can continue with goal directed behaviors and recovery. This is distinguished from adaption difficulty, which Mishel (1988) defines as those behaviors outside of an individual's standard and elevated levels of emotional distress.

Mishel's Theoretical Reconceptualization

Mishel (1990) was dissatisfied with the traditional linear model that influenced her original work and in order to more fully understand the concept on uncertainty she considered how uncertainty is viewed within Western culture. Her work identified the value of predictability, control, and mastery in health care, in particular with medical science. The expectation with medical science is to identify a certain cause of disease and with that information the illness can then be controlled. Equilibrium can be re-established. There is an expectation that a cause and

effect can be determined and success is judged by the degree that this goal is achieved. Certainty is the desired outcome. This attitude reflects a cultural bias for the preference of certainty and a course of achieving equilibrium as an end goal.

Mishel (1990) moved from a mechanistic way of thinking that embraced predictability, toward a probabilistic view of thinking that acknowledged uncertainty as a natural and expected aspect of many illnesses. Uncertainty was viewed as natural and an inherent part of reality. Life in general cannot be presupposed or concluded with precision (Mast, 1995; Mishel, 1990). In the reconceptualization and reformulation of her middle range theory, Mishel (1990) redefined her theory through the process of theory derivation. This is the process of using a parallel theory from another field to find explanation or predictions in one's own field of practice (Walker & Avant, 2005).

Mishel (1990) chose chaos theory (Poole, 1989), as the parent theory because it was a more dynamic theory. It is a theory that deals with open systems and the relationships between systems and outside forces. Chaos theory shifts attention to disorder, disequilibrium, and non linear relationships (Poole, 1989). This theory contributed to replacing the linear model of stress, coping activities, and adaption and changed the outcome portion of Mishel's original theoretical model (Lazarus & Folkman, 1984; Mishel, 1988). The theoretical assumptions from chaos theory that influenced this change were that in general, people function in a state of disequilibrium and major fluctuations enhance ones' receptivity to change. These fluctuations result in a re-patterning, which is evident in many levels of the system. Uncertainty in illness extends to many aspects of one's life, thus deconstructing meaning given to everyday events.

One is unable to eliminate uncertainty and there is an individual process of formulating a new reality (Mishel, 1990).

Uncertainty in illness is a source of instability that shifts a person from an original position toward a new state. Mishel (1990) contends that because the display of disorder is the predominant state, the formation of a new state remains unobservable. It is within this invisible state that a new structuring of a meaning and value is taking place. One is transitioning from one perspective of life toward a new and more varied orientation of life. The individual undergoes change, where the initial confusion and disorganization caused by the uncertain situation is replaced with acceptance of uncertainty as a part of reality, and an opportunity for personal growth (Tomey & Alligood, 2006). It is proposed that with an emphasis on logical and linear thought, that inflexibility and rigidity are promoted for conditions of uncertainty with the goal being to eliminate that which is unpredictable. This commitment to determinism interferes with the individual achieving a new level of stability and precludes one from discovering a range of other possibilities (Mishel, 1990).

Mishel's continued research work explored the effectiveness of nursing interventions to assist patients to manage uncertainty in illness. Mishel et al., (2003) conducted an investigation to evaluate certain individual moderating variables and responses to interventions in uncertain health-illness situations. The objective for this research was to determine nursing interventions that would assist one in managing uncertainty. The moderating variables selected were education, sources of information, and religiosity, which were variables that were identified in Mishel's (1981) original work. Education and sources of information were identified as resources for the individual and were measured by years of schooling and an investigator generated check

list of sources of information about prostate cancer that the individual utilized. These variables serve to enhance a knowledge base and promote information seeking which reduces uncertainty.

Religiosity was chosen as a means of professional and social support which Mishel (1981) identified as a key component in an individual's experience with uncertainty. When one has support in an uncertain situation there is assistance in clarifying the situation, finding meaning for the illness event, and a provision of an explanatory framework, all of which reduce uncertainty. Religiosity was measured in the categories of intrinsic and extrinsic religiosity. Intrinsic religiosity was defined as one's personal belief in God's role in one's health and was measured by the Multidimensional Health Locus of Control by Bekhuis, et al. (1995). Extrinsic religiosity is defined as one's participation in religious activities and was measured by the Brown and Gray scale (1987).

Mishel et al., (2003) designed a randomized interventional study to evaluate the research question of the effect of these personal moderating factors and the benefit of nursing intervention in uncertain situations. The sample size consisted of 239 men who had been recently diagnosed with prostate cancer. Participants were randomly assigned to treatment groups or control groups. Control group participants received the current standard of care. Treatment group participants underwent an eight-week intervention of weekly nurse intervener phone calls. These calls served to assess subject's cancer related concerns, the uncertainty associated with the concern, and the degree of threat posed by uncertainty. Based on this assessment, interventions were implemented and included reinforcing and validating views, providing information, activating resources, teaching, and communicating with other health care providers.

The results of this investigation demonstrated significant differences with treatment and control groups in the measures of patient knowledge, religiosity, and provider communication. The intervention group demonstrated a significant change in knowledge ($p = .002$), with those having less education directly benefiting from the intervention. Participants who had low levels of extrinsic religiosity in the intervention group demonstrated gain when compared to the control group. Those in the intervention group communicated more to their physician ($p = .008$). In patient-provider communication the treatment group demonstrated a significant difference on the amount of information that the patient shared with their physician ($p = .007$).

These findings support that the nursing intervention of assessment and education improved uncertain conditions for individuals. Those specific elements include evaluating the individual's perception of uncertainty as either a positive or negative occurrence and to determine the need and preference of information. Interventions included establishing a connection with patients for therapeutic support, educating individuals about anticipated or commonly experienced patterns of symptoms, and activating help to mobilize family support. In this study, the support offered influenced a change in knowledge level and enhanced communication with one's provider. Mishel et al., (2003) concluded that the explicit nursing intervention of education diminished uncertainty and improved one's ability to manage their illness.

Continued research work that utilized Mishel's Reconceptualized Uncertainty in Illness Model was done by Bailey, Wallace, and Mishel (2007). Their investigation explored the uncertainties in men with prostate cancer and the strategies they utilized during the watchful waiting period. This watchful waiting period is the time of medical surveillance and is proposed

as a reasonable alternative to treatment in older men with localized disease. However, this watchful waiting period is controversial, as more radical therapies, such as radiation therapy and prostatectomy are considered curative. Men with prostate cancer who undergo watchful waiting versus men with prostate cancer who had undergone alternative treatments were considered to experience more illness related uncertainty as they had to live with the uncertainty about their disease and the risk of cancer growth and metastasis.

A qualitative descriptive study utilizing structured interviews was designed to explore the problems and management of uncertainty of older men in the watchful waiting period. Ten men, who had been living with a prostate cancer diagnosis from four to twelve months, participated in this study and were interviewed with an interview guide at one time point. Mishel's (1990) Reconceptualized Theory of Uncertainty in Illness served as the organizing framework for the analysis. The domains of the model, which were identified as uncertainty, the appraisal of danger, and the appraisal of opportunity served to conceptually organize the select concerns of the study participants. Each domain of the theoretical model was supported by the experience of the men in this study who were undergoing watchful waiting.

In the domain of uncertainty, study participants reported ambiguity in the absence of symptoms, the imprecision of testing, and the question of treatment versus no treatment. In the domain of danger appraisal participants reported persistent worry and lingering doubt. They continually second guessed their decision to hold on more aggressive treatment options. The final domain of the theoretical framework was opportunity appraisal, where participants successfully managed their uncertainty through work, self care, keeping options open, the use of alternative therapies, and prayer. Some were able to minimize or redefine the cancer threat by

believing that the cancer may remain unchanged for a long period of time, trusting their physician and their expertise or that another health event such as a heart disease would be their likely cause of death.

The results of this study supported Mishel's Reconceptualized Theory of Uncertainty in Illness (1990), with those men who choose watchful waiting for a diagnosis of prostate cancer experiencing the following concerns. These men experienced uncertainty with the absence of physical symptoms, lack of consistent treatment guidelines, and concerns for disease progression. The appraisal of danger was described as a period of unrelenting concern and worry. In dealing with a crisis, these men cognitively redefined and shaped events in such a way that they became more positive or a new view of life was adopted. This cognitive reframing aligns with the opportunity domain of Mishel's (1990) framework with one being able to re-define the threat, and to believe in future more positive treatment options.

Uncertainty is primarily a negative and unconstructive aspect of chronic illness. It has been portrayed in the context of vagueness, ambiguity, lack of information, unpredictability, inconsistency, and unfamiliarity. Uncertainty in illness has been recognized as a significant stressor for individuals. In these circumstances, one is subjected to the uncertain situation of not knowing when a destined harm will occur. Mishel's (1988) work provides nursing with an inclusive theoretical framework by which the experience of uncertainty in illness can be more readily appreciated and comprehended. The original theoretical framework was organized in a linear model which incorporated three fundamental elements. They were the antecedents of uncertainty, the process of uncertainty appraisal, and coping with uncertainty. Mishel (1990) further expanded and reconceptualized her original theoretical work to include the unique

context of continued uncertainty and how one manages those situations in chronic illness.

Nursing research has supported the relationship between perceived negative uncertainty with detrimental characteristics of coping and adaption along with specific nursing interventions that will aid one in managing uncertainty in chronic illness (Baily, Wallace, & Mishel, 2007; Mast, 1995; Mishel, 1981; Mishel, 1984; Mishel, 1988; Mishel, 1999; Mishel & Branden, 1987; Mishel, et al., 2003; Mishel, Hostetter, King, & Graham; 1987; Mishel & Murdaugh, 1987).

Appraisal of Mishel's Middle Range Theories

Meleis (2007) guides the profession of nursing in evaluation of theoretical work that theories are dynamic and many are not all encompassing. However, when middle range theories are developed, caution needs to be employed that there is not a fragmentation of knowledge. Some restrictions with Mishel's middle range theory include utilizing a concept that continues to develop and become distinguishable with defined boundaries. The concept of uncertainty lends itself to over-attribution, where many elements of the experience are linked to the concept. Morse et al., (2002) described this as conceptual tunnel vision, where the concept of interest is evident in all aspects of the experience, making it difficult to reveal a conceptual framework for the concept of interest.

In Mishel's (1988) original framework the definition of adaption is made without reference or inclusion of a key nursing theorist, Sr. Callista Roy. Adaption, defined by Roy (1984), is more comprehensive and appreciates the many levels, modes, responses, and behaviors that act in concert for one to have an adaptive response. This is in contrast to Mishel's (1988) definition which was a behavioral desired outcome. In not utilizing or referencing the Roy Adaption Model in the development of her middle range theory, Mishel (1988) forfeited further

scientific contributions of theoretical precision on human adaptive responses (Tomey & Alligood, 2006).

Mishel (1990) redesigned her initial theoretical work in a two-year time period after the original model was published. No testing of the original model was found in this literature review. All research conducted included the theorist herself as an investigator, possibly leading to a myopic or less than keen critical appraisal in the model development. With Mishel, (1988; 1990) having more than one model published, those referencing her may overlook the most current work, as in the works of Guadalupe (2010) and Choi, et al., (2012). Both utilized Mishel's original framework in their studies.

Mast (1995) critiques the inconsistency of two distinct theoretical frameworks for the concept of uncertainty. Mishel's response to this criticism was that her original work (Mishel, 1988) was to be utilized in research conducted with those in the acute phase of illness and the theoretical reconceptualization (Mishel, 1990) was to be employed with those individuals who are enduring long term illness (Mishel, 1995). The later model developed by Mishel (1990) was designed to promote probable and varied individual outcomes. This non-structured design with diverse and wide ranging end points would hinder quantitative research investigation, leaving this middle range theory subject to question on usefulness. This criticism is substantiated because of the restriction with testing the theory and the impediment of the theory to provide empirical evidence for practice (Meleis, 2007; Peterson & Bredow, 2009).

Penrod: Conceptual Analysis of Uncertainty

In order to develop an expanded theoretical definition and determine the maturity of the concept of uncertainty, Penrod (2001) conducted a conceptual analysis. Concept maturity was

defined as a concept that can be readily adapted, a concept that has well delineated boundaries, and a concept that has described pre-conditions and outcomes (Morse, Mitchum, Hupcey, & Tason, 1996). To determine these objectives, Penrod (2001) employed a concept analysis utilizing a principled approach. A principled approach in a concept analysis is based on four principles derived from the philosophy of science (Cody, 2006). These four philosophical principles include the epistemological principle, the pragmatic principle, the linguistic principle, and the logic principle. Epistemology is defined as the nature and justification of knowledge. This principle focuses on whether the concept is clearly defined with distinctive attributes and that the concept is visibly placed in the literature. Pragmatism conveys the usefulness of the concept in the respective discipline. The application of this principle is to investigate the conceptual fit within the discipline and how the concept has been operationalized. The linguistic principle refers to the science of speech and language. The concept is evaluated for consistent use and within the appropriate context in a variety of circumstances. The logic principle examines the integration of the concept with other related concepts. The concept must hold defined boundaries when theoretically integrated with other concepts (Hupcey & Penrod, 2005; Morse, Mitcham, Hupcey, & Tason, 1996). It is proposed that this approach allows for a comprehensive examination of the concept and a closer theoretical definition being made possible by including both the quality and maturity aspects of the concept (Hupcey & Penrod, 2005).

Penrod (2001) conducted a comparative analysis of the concept of uncertainty across four disciplines; medicine, sociology, psychology and nursing. The concept was analyzed from the perspective of each of these disciplines, utilizing the four broad principles of epistemological,

pragmatic, linguistical, and logical. The results from this work found that the most mature scientific conceptualization was in the psychology. Medicine was determined to have a narrowly defined scope of the concept, with uncertainty pertaining to clinical decision making. Sociology was found to have a limited data source with only implicit definitions of the concept which prohibited a linguistic evaluation. In nursing, the concept was determined to be moderately mature, with evidence evolving in Mishel's theoretical framework (Mast, 1995). It was concluded that the concept of uncertainty was only partially mature, leaving room for further concept development.

Penrod (2001) proposed that when a concept is deemed only partially mature, that this situation could be modified by having a more inclusive delineation of the concept. A more global definition would include that uncertainty is a dynamic state in which one is unable to assign probabilities for outcomes, which causes distress and anxiety. The experience of uncertainty is ubiquitous in the reality of human life and it is mediated by self assurance and personal influences that may be either event focused or pertain to a situation that requires a more global world view. This enhanced definition more clearly embodies the individual encounter with uncertain situations, which leaves the individual incapable of a perceiving the future and without immediate direct hope or optimism (Morse & Penrod, 1999; Penrod, 2001).

When one is diagnosed with a chronic disease that will entail a significant illness burden, there is an initial intense personal struggle that ensues where one strives to gain control (Kralik, 2002; Penrod, 2001). This is a period of high uncertainty, where one lacks a frame of reference, as with the diagnosis of cirrhosis. The diagnosis of cirrhosis is a disease state that has few discernable symptoms, a course that is unpredictable and is a diagnosis that poses an

incongruence between personal expectations and reality (Lefton, Rosa, & Cohen, 2009). Mishel (1988; 1990) guides the nursing assessment for these individuals, that when one is unable to employ inference or a past position, that they are at risk for being incapable of employing coping behaviors. This inability leaves one vulnerable, where they are unable to adapt to the situation and remain in a state of internal confusion and disorder.

The ever-present disease state and illness encumbrance imposes a personal course that is entirely different than where one originally began (Koch, Jenkin, & Kralik, 2004; Kralik, Koch, & Price; 2004). Endurance in these situations entails utilizing coping abilities, exercising some personal control, forcing the boundaries that disease and illness impose, and surrendering security (Dewar & Morse, 1995; Kralik, 2002; Mishel, 1988). In Mishel's (1990) reconceptualization of her original theoretical model of uncertainty, she aptly portrays the experience of uncertainty with illness as the source that shifts one toward a different reality, where one accepts what they cannot control, and matures with the experience.

Chronic illness has been defined in both terms of time and quality. In the terms of time it is constant and long lasting and in terms of quality, chronic illness has been described as incurable and bad (Peace, 1996). Chronic illness is the consequence of the physical disease and it has a profound effect on many aspects in one's life (Nordenfelt, 1995). Those domains include physical limitations, psychological distress and economic loss, each of which diminish a quality of life for the individual. This next section addresses the topic of chronic illness and quality of life and includes the works of Stuijbergen, Seraphine, and Roberts (2000), Bays (2001), Haynes and Wyatt, (2008) and Taylor, Gibson, and Frank (2008).

Chronic Illness and Quality of Life

In order to understand variables that influence health promotion and quality of life in individuals with a chronic and disabling condition, Stuijbergen, Seraphine, and Roberts (2000), reviewed previous data collected in large sample of individuals afflicted with Multiple Sclerosis. The objective of this work was to investigate the variables that affect an individual's quality of life when they are experiencing a chronic disease and illness. The sample size consisted of 786 persons with Multiple Sclerosis who had completed a number of instruments that measured influencing variables on an individual assessment of quality of life. The findings supported that one's quality of life with a chronic condition is influenced by a number of multifaceted and dynamic contextual factors. The dominant factor was severity of illness, which influenced performance, ability, and role function. This finding supported previous work on chronic illness where there was an inverse relationship between severity of illness and quality of life (Stuijbergen, 1995; Stuijbergen, Seraphine, & Roberts, 2000).

Two original and fresh perspectives from this work included the characterization of acceptance and the mediating effect health care providers can have on an individual's quality of life, despite a severe disease course. Acceptance is differentiated as the integration of the disease into one's everyday life. When this can be attained, it is proposed that there is a direct effect on health promoting behaviors (Stuijbergen, Seraphine, & Roberts, 2000).

The severity of illness and associated disability are judged as the key determinants of quality of life. Although one may not be able to control a continued downward disease course, Stuijbergen, Seraphine, and Roberts (2000), proposed that intervening measures by health care providers may enable an individual to maintain, and perhaps even augment, an enhanced quality

of life. The most powerful intervening variable that emerged was resources, which was operationalized in this review as social support. This support included family, significant others, and health care providers. This finding is in direct accordance with Mishel's work (1988; 1990) where it is substantiated that social support aids an individual in clarifying the situation, allows one to find meaning with the event, and offers instructive information, all of which diminish uncertainty. The responsibility of those who are providing care is to attempt to curtail barriers in health seeking behaviors and to further an individual's self efficacy. Both of these actions are central in nursing care, where caring relationships are coupled with skilled caring behaviors, to impact a beneficial result for those receiving nursing care (Gastmans, Dierckx, & Schotsmans, 1998; Stuifbergen, Seraphine, & Roberts, 2000).

Bays (2001) conducted a research synthesis on existing research material which investigated quality of life for stroke survivors. The purpose of this work was to provide direction for future nursing research by providing a cumulative summary of present research, which would yield a maximum amount of information. The investigator identified 39 studies in the literature that focused on quality of life for stroke survivors.

Despite the challenges of inconsistent statistical reporting, Bays (2001) was able to identify key variables, through regression analysis across collective study data that were considered to be either a positive or negative influences on quality of life for stroke survivors. Those variables were identified as activities of daily living and depression. Activities of daily living had a positive effect on quality of life for stroke survivors and included level of independence, functional ability, social support, and health care resources. Depression was associated with a negative effect on quality of life and the gravity of depression was influenced

by the amount of cognitive impairment, stroke severity, and aphasia. These findings draw attention to individual loss and the potential consequence of depression, which has a potent effect on an individual quality of life. The researcher suggested further study of individuals enduring a major health event to investigate other variables that affect one's quality of life, to determine if these variables change over time, and to discern what interventions enhance a quality of life for the individual.

Haynes & Watt (2008) conducted a phenomenological study to investigate the lived experience of dealing with a chronic illness in those individuals who presented themselves as gaining from the illness experience and continuing to enjoy a perceptible quality of life. The goal of the study was to acquire an understanding of the individual characteristics of persons living life with a physically debilitating illness who viewed themselves as healthy and to identify common characteristics, viewpoints, and behaviors that elicited healthy behaviors, a productive quality of life, and successful coping. The focus of the study was on resilient individuals, with sample study participants being referred to the researchers from peers, family, or health care providers who perceived these individuals as healthy despite having a physical disability.

The sample size consisted of eight participants, each having had lived with a chronic disease for a duration of greater than six months. Five themes were reported in each of the interviews and they included that family support and spirituality were key mechanisms to successful coping, participants did not make illness the focal point of their life, they each committed to living life successfully, regardless of limitations, they compared themselves to those who were in worse situations, and attributed their success in handling a chronic condition to an inherent personality make-up and role models. The personality traits included an inner

drive and persistence, and role models were identified as parents who exemplified the skills needed to be successful in adapting to adverse life events.

Haynes and Watt (2008) developed two concepts from the above themes, spirituality and focus. Each of the participants related that having a healthy support system involved both family and a Higher Being. These were primary factors that influenced coping with their illness. Additionally, study participants focused on others versus their illness. Their primary goal was to help others to be successful and this was evident in their directed energy with family members. This interest in others was deemed as not only support for the individual dealing with a chronic illness, but served as a motivating factor to keep the individual functioning at a higher level than the disease process would normally allow.

There are two major issues that have restricted quality of life research. One is that there is no universal definition of quality of life. It is an expression that is often used interchangeably with other terms that have conceptually similar meanings, such as life satisfaction, well being, and functional status (Eales, 2000; Haas, 1999). Secondly, it is a dynamic construct that is continually modified over time by coping skills, adaption, and self control. One time measures may be insufficient to capture the changes in one's assessment of attributes of quality in their life during a prolonged and varying disease and illness course (Eales, 2000). It has been proposed that because quality of life is such a uniquely personal perception, existing measurement tools need be supplemented with opportunities for patients to add on items that they consider important (Gill & Feinstein, 1994).

In order to develop a definition of quality of life that is more representative for those experiencing chronic illness, Taylor, Gibson, and Franck (2008) conducted a concept analysis

based on published work. The analysis was guided by methodology proposed by Walker and Avant (2005).

Definitions of the concept of quality of life were derived from the works of Meeberg (1993), Cooley (1998) and Haas (1999) and included an overall present satisfaction and a subjective sense of well-being. It was a dynamic state that was influenced by various dimensions of an individual's life, which included one's values, current life circumstances, and the context of culture. The impact of disease, treatments, physical symptoms, functional status and interpersonal relationships all affected the congruence between actual life conditions and one's hopes and expectations, which influence an individual's appraisal of their quality of life.

Defining attributes are the recurrent characteristics of the concept and are considered to be the essence of the concept (Walker & Avant, 2005). Based on the literature review conducted by Taylor, Gibson, and Franck (2008) on the impact of chronic illness on one's quality of life, the researchers determined defining characteristics of quality of life. These included that a quality of life assessment is subjective and unique to each individual. Quality of life judgment is multi-dimensional and includes aspects of physical, psychological, and social function. Physical function includes the impact of illness on appearance, psychological function includes coping, and adaption and social function incorporates the interaction with others. Quality of life is a dynamic state and is influenced by the illness trajectory and the impact that ill health has on goals and ambitions.

The example cases were based on the author's clinical experience and included two liver transplant recipients. In the cases presented, one portrayed a good quality of life post transplant, with the individual regaining health, reaching personal goals, and maintaining a close connection

to others. The second case depicted a poor outcome with post op issues of rejection, renal failure and diabetes. In each of these examples, the individual had a different experience of quality of life after liver transplant. Their quality of life was persuaded by the illness trajectory, where favorable health events contributed to a good quality of life and the unforeseen being a major factor in a poorer quality of life.

Antecedents are necessary conditions for the concept to be present and contribute to the occurrence (Walker & Avant, 2005). The antecedents to quality of life included the ability to make a decision and the capability to evaluate one's life. Consequences are those factors that follow the occurrence of the concept and could be either positive or negative (Walker & Avant, 2005). Positive outcomes for quality of life are defined as satisfaction and acceptance with one's circumstances. In contrast, a negative outcome for quality of life included dissatisfaction and a non-acceptance of circumstances.

Empirical referents are the events that demonstrate the existence of the concept and include measures and appraisal of the concept (Walker & Avant, 2005). For the concept of quality of life, measures of the conceptual attributes include the appraisal measures of satisfaction, happiness, and individual statements about feelings of satisfaction or dissatisfaction. The researchers noted that there are issues in the measurement of the concept of quality of life, with the assessment of this concept, at times being dependent on the researcher's conceptualization of quality of life versus an individual's view of their life (Taylor, Gibson, & Franck, 2008).

Following this concept analysis, the investigators proposed a definition of quality of life for those with chronic illness. They contended that quality of life with chronic illness is

subjective, multidimensional, and dynamic. Quality of life is unique to each individual and includes aspects of physical, psychological, and social function. Quality of life is dependent upon the illness trajectory and involves the achievement of goals and aspirations, and the constraints imposed on those desires by ill health and treatment (Taylor, Gibson, & Franck, 2008).

Although this attempt in defining quality of life gives a definition that is closer to the essence of the concept, the description lacks specificity and does not include the context of one's values, cultural influence, current circumstances, or the connections one has with others. These limitations could be attributed to the Walker & Avant (2005) methodology utilized by the investigators. Hupcey and Penrod (2005) stipulate that when concepts are ever changing and evolving over time, as with the concept of quality of life, the Walker and Avant (2005) method of concept analysis falls short in one major area. This methodology captures the critical essentials of the concept at a specific time point and bears the constraint of having the concept to not be as well understood as the authors would have intended.

There have been challenges in measuring the concept of quality of life because it is personal, dynamic, and lacks a universal definition (Earles, 2000; Haas, 1999). In the conceptual analysis conducted by Taylor, Gibson, and Frank (2008), they proposed that the concept of quality of life is personal, multidimensional, and dynamic. Quality of life includes all aspects of individual function and it is dependent on the illness trajectory. The effect of the illness trajectory negatively influences quality of life by impeding the achievement of goals and ambitions. The product of this concept analysis lacks a solid operational definition, which would preclude measurement. Additionally, some of the essential characteristics of the concept may be lacking. Despite these deficiencies, their work developed a stronger link between impression and

language, which supports both truth, and an understanding of that which is not empirical (Paley, 1996).

For those that are afflicted with chronic disease and illness, there are numerous variables that have a negative effect on one's quality of life. They include both the severity of the disease and the illness. One undergoes the loss of health, function, and their role in life. All experience suffering. This suffering encompasses both the direct physical deficits and the indirect aspects of suffering, which is the emotional response to that loss. The following section addresses the concept of suffering and includes the works of Morse and Johnson, 1991; Wainwright, 1995, and Nordenfelt, 1995.

Chronic Illness and Suffering

Serious chronic illnesses affect both the individual and all of those significant others in one's life. In order to expand on the medical model of illness, where one's symptoms are the primary target of investigation, Morse and Johnson (1991) took an alternative approach to understand individual coping behaviors with a chronic disease process. Their work investigated not only physical symptoms but the human response to those symptoms.

Central to their work was the concept of coping. Coping refers to the problem solving efforts that one makes when the demands one faces are highly relevant to one's welfare and these demands tax one's adaptive resources (Lazarus, 1991). Coping is an emotional, as well as a cognitive process, that requires the individual to make a series of judgments about the potential effects of the situation and the end result that it may have on one's well being. These effects can be positive and include coping with those events that hold promise as well as those events that produce distress as a result of loss (Brammer & Abrego, 1981). A distinct feature of coping

activities is that they are a conscious choice, versus adaptive activities that require no individual effort (Tennen et al., 2000).

Morse & Johnson (1991) matched five grounded theoretical works (Chasse, 1988; Johnson, 1988; Lorenz, 1988; Norris, 1986; Wilson, 1988) on the stages of illness and coordinated the findings from these works with the experience of disease symptoms and the behavioral response one may have to those physical symptoms to develop the Illness Constellation Model. The model offered a more inclusive view of the human experience with chronic illness. Up until this work, much of the investigation on chronic illness offered only a narrow view of this human encounter. The authors asserted that the reason for this less than complete comprehension was because a medical model approach was utilized to understand an individual's response to a specific diagnosis. With a medical model approach to illness, the focus is primarily on the patient report of symptoms. When physical symptoms are the exclusive assessment for understanding human responses to specific diagnoses, one can only ascertain an a priori perception of behaviors, leaving the complex process of understanding an illness experience only partially appreciated (Rogers, 2005).

The framework developed by Morse & Johnson (1991) included four stages. The first stage was that of uncertainty, where an individual was aware that something is wrong. Symptoms intensified over time prompting medical attention. The second stage was that of disruption, with medical attention being required. Although this stage was marked with disorder and vulnerability, at the ending of this stage, one gained an understanding of what is happening to them, resulting in some personal control.

This second stage is followed by the striving to regain self. This is the third stage of the process where one commits to the struggle, renegotiates roles, seeks reassurance, commits to goals, and attempts to regain individual command. The last stage is that of regaining wellness where one's charge is to no longer be illness dependent, and to gain mastery over the situation. In this stage, full closure is not afforded to those with diagnoses that are chronic and progressive, versus those that bear an acute and resolvable event (Morse & Johnson, 1991).

The concept of suffering was pervasive in the five matched grounded theory works that Morse and Johnson (1991) synthesized into the Illness Constellation Model. The illness experience included physical pain, the psychological discomfort of illness, the pressure to endure, being institutionalized, an uncertain future, and the imposed estrangement from everyday life activities (Chasse, 1988; Johnson, 1988; Lorenz, 1988; Norris, 1986; Wilson, 1988). Morse & Johnson (1991) assessed that suffering was a central experience for individuals in the Illness Constellation Model and asserted that it is the responsibility of nursing to moderate this occurrence. The process of minimizing suffering includes the directed nursing actions of reducing the discomfort associated with illness, understanding the distress with changing one's role in life, and the hesitation that comes with a future that is vague and ambiguous.

The Illness Constellation Model provides an improved comprehension of the illness experience from the perspective of both the individual and loved ones. The experience that one has with serious illness has a dual effect on both the individual and their significant others. When there is a loss of what is routine and ordinary, as in a serious illness experience, there is not only the personal effort to determine a course of action, but there is a change in the interactions one has with those that are close. This individual needs more from those significant relationships.

Without the help of loved ones, these individuals will struggle more through the stages of disruption and striving to regain self. This effort will be especially difficult for those who will not reach the stage of regained wellness. Finally, this work supported the continued investigation of both the patient's perspective and the perceptions of those who support the individual through the illness experience, in order to gain insight to provide for better care strategies (Morse & Johnson, 1991).

The four stages of uncertainty, disruption, regaining self, and regaining wellness of the Illness Constellation Theoretical Model align closely with the work of other theorists. Taylor (1983) proposed in her research that one can attain affirmative coping abilities when there has been success in regaining some mastery and influence in the situation, as with one being able to recapture a sense of self and wellness. Mishel (1988) maintained that uncertainty exists when an individual lacks a frame of reference with events that are unclear, indistinct, and inconsistent. It is this ambiguity that places one at risk for unease and apprehension. Concomitant work done by Lazarus (1991) contended that after an initial assessment of harm there is a secondary appraisal of the situation. It is in this secondary appraisal that one determines individual control and power over the situation. If one can ascertain a personal influence with the circumstances, it is then that problem focused coping skills can be employed. These assertions closely parallel Morse and Johnson's (1991) stages of uncertainty and disruption followed by recovery of self and wellness, where one's sense of self is no longer contingent on the illness event.

Wainwright (1995) conducted a grounded theory study on the experiences of life before a liver transplant. The research study had three objectives. These included the exploration of living with end stage liver disease, to search for the problems experienced by these individuals, and to

provide insight to health care professionals on the individual impact of decompensated liver function. Ten participants were interviewed for the study. Transcendence was proposed as the core variable, which accounted for the patient being able to overcome the demanding aspects of end stage liver disease and transcend to a successful end with the opportunity for a liver transplant. Two themes emerged from this study, which were identified as becoming ill and not living. Becoming ill was described as interpreting symptoms, loss of physical stamina, a general decline in health, and learning to manage illness. This was followed by a continued decline in physical and mental reserve which was identified as not living. The individual at this stage was now disabled and no longer independent. Within this stage, individuals maintained a continued desire to return to normal and avoid death. This hope was sustained with the anticipation of a liver transplant.

The themes of becoming ill and not living fittingly describe the aspects of end stage liver disease where one is deprived of a high quality of life. Despite this encumbrance, individuals were able to transcend this experience and maintain an optimistic future perspective. This work closely aligns with the previous work of Morse and Johnson (1991) and in the development of the Illness Constellation Model. Suffering was determined to be a central occurrence in that work, which suitably portrays the experience of becoming ill and not living. The stages described in the Illness Constellation Model of uncertainty and disruptions are comparable to the theoretical scheme of becoming ill and not living. Regaining self and wellness parallel the core variable of transcendence, which was identified in Wainwright's work (1995).

When one is afflicted with a chronic disease that is long term and irreversible, they endure emotional consequences of those physiological processes or malfunctions. Chronic

disease and illness impose suffering on an individual and hamper their quality of life. Suffering for these individuals has been characterized as direct and indirect suffering (Nordenfelt, 1995). Direct suffering is equated with the physical defect, injury, or impairment that is associated with the disease event. Indirect suffering is the result of the individual becoming aware that they are experiencing something contrary to their desires. It is a negative emotion and it is equated with unhappiness and a state of severe distress.

There is not a cure potential for those individuals afflicted with chronic disease. Among the things that health care providers can do for these individuals is to limit suffering and thus improve their quality of life (Jensen, 2013). The following three imperatives to limiting suffering are suggested by Nordenfelt (1995). These include giving information within a knowledge state that understands the impact of a disease diagnosis, maintaining an emphasis on hope and positive strategies for the fight against the disease and illness, and helping the individual to cope with the disease event by assisting them to renegotiate vital goals and mobilizing social support.

Despite the loss, sadness, and anguish that one faces with chronic illness and the unconstructive effect these variables have on individual suffering and quality of life, there are accounts of the ability to overcome the harsh aspects of disease. Wainwright (1995) identified the individual capability of transcendence where hope and optimism remained. When one was able to integrate the disease into everyday life, there was an element of acceptance and this is proposed to have a direct effect on health promoting behaviors and an improved quality of life (Stuifbergen, Seraphine, & Roberts, 2000). The support of others, particularly the role of health care providers is a significant factor in contributing to a different quality of life for these

individuals. Those actions include the limiting of suffering, by employing compassionate and empathetic communication skills, sustaining approaches for endurance, and assisting the individual in activating the support of others (Nordenfelt, 1995).

The influence of a stressful event and the ability of an individual to cope within these situations were investigated in the noteworthy work of Lazarus (1991). He identified key coping modes and behavioral responses associated with these coping modes. His work on stress and coping modes is addressed in the following section of this literature review.

Stress and Coping

A common denominator to any untoward change in life is stress (Lazarus & Folkman, 1984). Although stress is an inevitable part of life, the variance in human performance rests on how one copes with the event. These coping responses are established by either the stimulus itself or the individual's response to that demanding event. Stress stimuli are defined as the intruding occurrence. This description presumes that certain situations are generally stressful for individuals. The response to this demanding event is one's reaction. This is influenced by the magnitude of the incident, the extent of control one has, and the mandated adjustments that are required. What is qualitatively distinct in this element of the stress equation is that stress reactions markedly differ with each individual. Depending on what is at stake, the perceived threat and challenge affects an individual's ability to manage the situation. Control in a stressful encounter is the prominent factor that influences coping. As disease and illness emits physiological stress and toll, it is human coping abilities that determine staying power. This emotional steadiness and stability translates to focused actions that support problem solving and

having some command and confidence with the situation (Selye, 1978; Lazarus, 1991; Walker, 2001).

Lazarus (1991) denoted three major coping modes. These included direct action, vigilance and avoidance. Direct action was equated with information seeking. This action influenced the modes of coping actions of vigilance and avoidance. It was postulated that with events of high uncertainty there was less individual ability to utilize the direct action of information seeking and vigilance. This claim was based on the previous research work conducted by Monat, Averill, & Lazarus (1972). It was determined in this study, that with the condition of temporal uncertainty, when the timing of an objectionable was unknown, there were higher occurrences of avoidant modes of coping and lower levels of affective arousal.

Without the ability to utilize direct action as a coping mechanism, one encounters less capability to counter a threatening situation, and is prone to exhibiting emotional reactions to stress (Mishel, 1980). What remains indeterminate are the types of events that foster vigilance or avoidance behaviors or how coping methods bear up to the persistent input of negative health events that are a part of a chronic disease that has a tentative trajectory (Corbin & Strauss, 1991; Robinson, et al., 1993). It is proposed that collective and cumulative loss over time eradicates one's coping abilities (Lazarus & Folkman, 1984; Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2004). This phenomenon is addressed in the next section of this review.

Coping with Chronic Illness

The question of how one manages a chronic illness along with continued demands of frequent psychological adjustments was the focus of the work of Lazarus & Folkman (1984) with continued contributions to this theoretical framework by Folkman & Moskowitz (2000; 2004).

Coping processes are a complex interaction between the individual and the environment. Both the person and the environment influence each other equally. An individual initially considers the threat or promise associated with the event. This appraisal involves two components which include a primary and secondary assessment of the situation. In the primary appraisal, the individual assesses the immediate peril and confrontation (Lazarus & Folkman, 1984).

Understanding one's initial response has a pivotal role for health care providers. This primary judgment shapes future undertakings and goals and is a predictor of potential anxiety and depression (Leventhal, et al., 2008). It is within this initial cognitive appraisal that the quality of the emotional response guides impending coping behaviors (Folkman & Moskowitz, 2004).

Secondary appraisal is a cognitive evaluation of one's responsibility, problem solving and emotionally directed coping attempts. This appraisal begins the anticipation of potential changes that may be required in one's circumstances. In this phase, it is individual power that is the central issue. When an individual perceives that the situation is controllable, they are able to engage in more problem focused coping skills of problem solving, information seeking and positive re-appraisal, which have been equated with more affirmative personal modifications and healthier overall adjustment (Lazarus & Folkman, 1984; Folkman & Moskowitz, 2000). As one ascertains the ability to manage the event, coping resources are engaged to regulate distress (Folkman & Moskowitz, 2004).

Adjustment to chronic illness is multi-dimensional and includes both interpersonal and intrapersonal dimensions. The interpersonal aspect of adjustment pertains to the individual's personal relationships with friends, family, and health care providers. The intrapersonal dimension of adjustment includes the realms of a cognitive, emotional, behavioral, and physical

functioning. Within each of these domains, adjustment to chronic illness includes more than what is immediately confronting the individual. One adjusts to difficult health situations holistically and this includes a mental, physical, behavioral, and social response. The more severe and prolonged the demands and burden of a chronic illness, the more complicated the individual adjustment (Stanton, Collins, & Sworowski, 2001). The research work of Taylor (1983) and the theoretical framework developed Stanton, Collins, & Sworowski (2001) extended insight on factors that either help or hinder the individual confronting chronic illness. Their work is discussed in the following section.

Adjustment to Chronic Illness

Human beings have a remarkable ability to carry on despite dire personal hardship. This formidable human reserve prompted Taylor (1983) to investigate the re-adjustment process in individuals who have faced a life threatening health event. Over a 2-year period 78 women, diagnosed with breast cancer were interviewed and from those interviews Taylor (1983) offered a theoretical framework on cognitive adaption to threatening events. The methodology utilized in this study closely aligns with a Grounded Theory approach, but the researcher does not identify this research method in her work. Three important themes emerged, and included the search for meaning in the experience, an attempt to regain mastery over the event, and an effort to enhance one's self esteem. Each of these findings will be further addressed along with the author's determination of a core variable.

Meaning was the personal ability to comprehend an event and it was a central element in purposeful and determined behaviors (Taylor, 1983) An essential conceptual characteristic in the search for meaning was that it was a uniquely personal experience, being relevant only to that

certain individual in an exclusive situation (Skaggs & Barron, 2005). In this study, the search for meaning required an understanding of the event and involved a personal analysis of why the event happened. The meaning that one attached to the event was tailored by an individual interpretive process, which one employed to manage that which one encountered in life (Blumer, 1969). The initial finding in this study for the search for meaning was that it required a restructuring of personal priorities and modification of one's current life position. Ordinary and everyday activities were given a lower precedence than relationships and pleasurable life activities (Taylor, 1983).

The second theme that emerged in this study was in the ability of one to gain mastery over the situation. Unexpected and abrupt life events challenge personal control and one's ability to manage circumstances. Gaining a sense of mastery was demonstrated in efforts at personal command over related aspects of the illness. This sense of mastery could be fulfilled by other than direct efforts to control the disease and include behaviors such as information seeking and active participation in care activities. The notion of mastery was associated with a sense of coherence, feelings of well being, and enhanced coping abilities in aversive events (Taylor, 1983; Skaggs & Barron, 2005).

The final theme that emerged in this study was a process of self enhancement (Taylor, 1983). Threatening events take a toll on one's self worth and self regard. In an effort to restore self esteem, individuals in this study reported two personal actions. The first was that with an inner emotional adjustment, most participants reported the ability to take personal benefit from an adverse event. The second action was for individuals to compare themselves to others. In this study, women chose downward comparisons to enhance self esteem. Their dimension of

difference was to compare themselves to those that were worse off. This finding opposed prior predictive social comparison models, where it was believed that individuals would compare themselves to those doing slightly better in order to grasp more effective coping skills.

Important clinical information in this domain of the investigation was that social and psychological processes engage to formulate significant results. Women intentionally made comparisons which fostered their self esteem (Taylor, 1983).

The core category was identified as illusion and the author maintained that this was the underlying quality that allowed for successful individual efforts of resolve. The concept of illusion was characterized as one's ability to view the known facts in a more positive light versus believing that which is opposite of reality. Illusion in this study was believed to be an essential element in the individual's process of adjustment and adaption to threatening events. Inner belief and conviction that one could assert control over their circumstances was constructive in two areas. This personal confidence contributed toward maintaining a sense of self by allowing for an orderly and structured processing of information and fostered the generation of determined behaviors. In this work the author purports that a sense of meaning, mastery and self enhancement are enabled through the specific achieved cognitions where a positive perception or illusion affords an individual the capability, to not only face a threatening situation but to persevere, despite setbacks (Taylor, 1983).

The definition of illusion by Taylor (1983) is equivalent to the later theoretical work of Mishel (1988), where the term was defined as a personal positive conviction in an uncertain situation. This optimistic outlook fostered the individual viewing the uncertain situation as an opportunity. When one has the ability to view circumstances more constructively, Mishel (1988)

contended that hope was cultivated and that one could more readily employ effective coping strategies. These coping skills influenced a positive outcome in uncertain situations which Mishel (1988) identified as adaption and defined this as one being able to return to usual and routine behaviors.

The purpose of Taylor's (1983) work was to understand the experience of those living in an arduous health-illness situation. Taylor (1983) maintained that when individuals experience adversity they respond with cognitive adaptive efforts that enable a certain level of assenting psychological functioning. There are aspects in illness that can be controlled as well as those that cannot. In situations where control is possible, one needs to control what one can, and relinquish efforts to control that which one has no power (Taylor, 1983).

In an effort to understand the specific meaningful points of the impact that disease has on adjustment, Stanton, Collins, & Sworowski (2001) investigated the works of two prominent conceptual frameworks of human functioning and coping with the stressful experiences associated with chronic disease. These works included that of Lazarus and Folkman (1984) which delineated coping skills that would influence a positive adjustment and the theoretical framework developed by Maes, Leventhal, & de Ridder (1996) which outlines the factors that contribute to one's adjustment to a chronic illness.

The work of Lazarus and Folkman (1984) proposed that the central determinants of adaptive outcomes included an initial cognitive appraisal of potential harm, a secondary appraisal of the individual's ability to control or manage the situation, and the employment of coping strategies. These coping strategies were the cognitive and behavioral efforts to manage the external or internal demands imposed by the circumstances, which have been appraised to be

difficult and challenging. Lazarus and Folkman (1984) proposed that when an individual is able to engage higher level coping skills, such as information seeking, rational thinking and problem solving that there will be a more favorable or positive adjustment.

In the theoretical framework developed by Maes, Leventhal, & de Ridder (1996), the ability of one to adjust to a chronic illness included contextual factors, the characteristics of specific disease situations, and the consequences of the disease experienced. Contextual factors were categorized as other life events, demographic attributes, and the cultural and social environment associated with the disease situation. The characteristics of the specific disease included the disease in general versus a specific aspect of the disease, as in the diagnosis of epilepsy versus a seizure event. The consequences of the disease and symptoms were identified as controllability, duration, cause, the threat of unrealized life goals, and a change in self identity.

The broad conceptual categories of coping (Lazarus & Folkman, 1984) and adjustment (Maes, Leventhal, & de Ridder, 1996) were utilized by researchers to develop a theoretical framework on specific influences of individual adjustment to chronic illness. There are three major conceptual pieces to Stanton, Collins, and Sworowski's (2001) theoretical framework. These are the contextual factors that contribute to adjustment in chronic illness, an individual cognitive appraisal, and the employment of coping activities, all of which influence a psychological, social and physical adjustment. Contextual factors that contribute to an individual's adjustment include a personal context, the disease itself, and environmental factors.

Within the personal context, the researchers included both social support and an interpersonal context. Social support was considered to be the interactions that one has with others where one gains emotional comfort, information, concrete aid, or an enhanced self regard.

These specific factors would aid an adjustment to chronic illness. This description of social support is comparable to the earlier work of Mishel (1988), where the theorist holds that social support in uncertain situations eases the individual experience of understanding and ascribing meaning to the event, while simultaneously averting isolation.

The interpersonal context within the model was represented by both personality characteristics and dispositional optimism. Personality characteristics were described by Bolger (1990) as having five basic factors. These fundamental characteristics include openness to experience, conscientiousness, extraversion, agreeableness, and neuroticism. Those individuals who fit the domain of openness to experience would demonstrate ingenuity, a preference for variety, and possess creativity. Personality traits associated with conscientiousness include those attributes of organization, self discipline, and goal orientation. Extraversion is equated with characteristics of being assertive, holding a positive affect, and preferring the companionship of others. Individuals who would be described as agreeable reflect compassion, cooperation and generosity. Each of these personality traits holds an underlying optimistic view of human nature (Digman, 1990).

Neuroticism, as a personality trait, is associated with those individuals who display a tendency to experience negative emotions easily, such as anger, anxiety, and depression. It is a personality trait that has been linked with a low tolerance for stress, a pessimistic outlook, and emotional reactivity. Although, it is proposed that each of the five personality attributes would influence one's adjustment to chronic illness, neuroticism was the factor cited by the author's as a highly identifiable risk factor that would be associated with maladjustment. These individuals

would be prone to employ more avoidant behaviors and less approach oriented coping skills (Bolger, 1990; Digman, 1990).

Dispositional optimism is a construct that is defined as a general expectancy for a favorable outcome (Scheier & Carver, 1985). This construct was examined as a predictor of well being by Carver et al., (1993) in patient populations that had diagnoses of cancer, heart disease and HIV. The findings from this research work supported that optimism may be an important protective factor in adjusting to chronic illness. Individuals who held generalized expectancies for positive outcomes were more readily engaged in approach orientated coping strategies and goal directed behaviors. The researchers proposed that those who hold this attribute of optimism may transform a threatening situation into a favorable circumstance by being more capable to employ approach oriented coping strategies and affective social support, as well as reducing disease related threat appraisals and avoidant coping. When assessed in the earliest phases of diagnosis and treatment it was suggested that earlier interventions would promote a more favorable adjustment outcome (Stanton, Collins, & Sworowski, 2001).

The disease component of the contextual factors that contribute to an individual adjustment include the disease course, the treatment specific variables, and the particular disease characteristics. These explicit characteristics are identified as severity, controllability and predictability. The degree and complexity of each of these factors would be influential on adaptive outcomes.

Environmental factors included in the framework were portrayed within the context of the environment, culture and interpersonal perspectives. The researchers depicted the environmental influences to include both concurrent life events and chronic stress and tension.

Those experiencing more strain and external stressors to the disease itself would have further struggle with adjustment. Cultural factors influenced an individual's susceptibility, symptom awareness, and interpretation of somatic and emotional changes. Each of these categories would influence an adjustment consequence.

The cognitive appraisal and coping processes of the model closely align with Lazarus and Folkman's theoretical framework (1984). There is a primary appraisal of the stressful encounter and the significance that this has for the individual. It is an assessment of harm, threat, and challenge and has been presented as having a pivotal role in stress and coping. A secondary appraisal is the individual's capacity to manage or change the situation. Underlying this secondary assessment is individual control. The more control that an individual has in the situation, the more problem focused coping activities will be employed (Lazarus & Folkman, 1984). A central quality of chronic disease is that control over disease progression is not guaranteed. In this predicament, individuals are likely to shift attention from what is uncontrollable to that which is controllable, with realms that are responsive to control contributing to better adaption (Lazarus & Folkman, 1984; Taylor, 1983).

Coping processes were individual actions that were implemented in an attempt to either solve the problem or manage the emotions incurred with the stressor. These coping strategies included seeking social support, active positive reframing, information seeking and problem solving. When employed, these actions supported associations with higher levels of adjustment versus avoidant behaviors. The latter may serve initially to temporarily reduce the effects of the acute stressor by preventing one from becoming overwhelmed. However, over the long term

these behaviors have had an untoward effect on adjustment (Lazarus, 1991; Stanton, Collins, & Sworowski, 2001).

The theorists maintain that the relationship between contextual factors, an individual's cognitive appraisal, and the employment of coping strategies will influence an outcome of a psychological adjustment, a social adjustment, and a physical-health adjustment. The contextual factors of personality trait, the disease and treatment course, and the environmental and interpersonal context are antecedent factors to the situation. These are influences which will either aid or deter the individual's cognitive appraisal and coping processes. An initial appraisal of imminent harm is followed by a secondary appraisal, where individual power in the situation is determined. When the individual has a personal influence in the situation, the theorists contend that adaption will occur psychologically, socially, and physically (Stanton, Collins, & Sworowski, 2001). The definition of these adaptive tasks is adopted from the prior theoretical works of Taylor (1983). In her work with cognitive adaption to threatening events, Taylor (1983) determined that successful adjustment involves sustaining reasonable emotional balance, a sound self image, maintaining close relationships, finding meaning, with the event and maintaining mastery over one's life. There is a preservation of a functional status, a perceived quality of life, absence of a psychological disorder, and a low negative affect. Positive indicators of adjustment include maintaining a positive mood and retaining purpose in life.

The work of Stanton, Collins, and Sworowski (2001) expands the understanding of an individual who is coping with chronic illness by including the contextual factors of the disease itself, environmental factors, and personal attributes. These factors influence both the individual appraisal of the situation and the employment of coping activities. Individual control over the

situation is again the fundamental driving factor with one being able to employ problem focused coping skills and realizing a positive end outcome.

A pictorial of this theoretical model is depicted as follows.

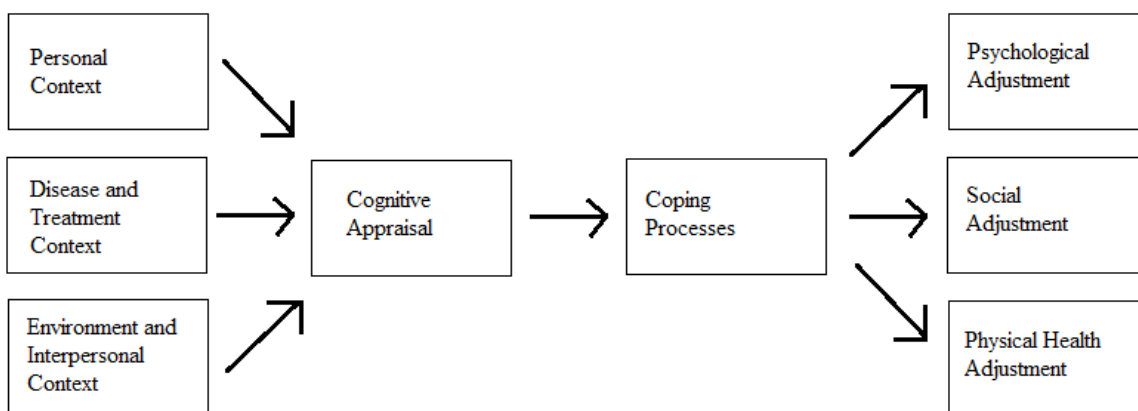


Figure 1. Individual Adjustment to Chronic Illness.

It is with the clinician's broader understanding and perspective that there can be a disentangling of the complex relations and multiple influences on how one adjusts to chronic illness. With this knowledge, health care providers are able to intentionally intervene to persuade a favorable patient outcome, where one has the ability to adjust psychologically, physically, and socially. Taylor (1983) and Stanton, Collins, and Sworowski (2001) contend that individuals possess the power to favorably adjust to alarming health events when they can respond with cognitive adaptive efforts that serve to protect, restore, and improve one's current state.

The following section closes this segment of the literature review. Included in this portion are summary statements on the research related to chronic illness and the importance of further nursing inquiry on this topic. The section is concluded with specific attention to the diagnosis of

cirrhosis as a chronic illness and the need for further nursing study to develop effective interventions that will improve their well being.

Nursing and Chronic Illness

Research in the field of the chronic illness experience demonstrates that the human encounter with this event is anything but commonplace or ordinary. Theoretical models have served to construct collective experiences and responses to chronic illness into a framework that aids health care providers to understand this complex human situation at a conceptual level. At this conceptual level, there are common and similar patterns of human response. These responses include activating coping mechanisms, adjusting to untoward events, engaging resources, dealing with uncertainty, and accepting a situation that has negative meaning for the individual.

It is in the development of general knowledge that there is a common ground to understand complex events. However, when concepts become acceptable markers for understanding the human response to illness, it is contended that these labels can impede a considerate individual approach. Many equally powerful influences are less visible when one focuses solely on knowledge that is general and transferrable (Corbin & Strauss, 1991; Woods, et al., 1993). There is the risk for that which remains obscure to be less articulated. What continues to be understudied in those afflicted with chronic disease is to align the unique individual response to a particular diagnosis with that which has been proposed to be typical phases of the illness journey. Overcoming this limitation requires continued attention on the individual, with the uniqueness of their experience being the basis for developing a more sensitive and complete provider response. As effective interventions in specific chronic disease populations are developed and catalogued, more holistic approaches can be constructed, which will add clarity

and transparency to this complicated phenomenon identified as the chronic illness experience (Corbin & Strauss, 1991; Michael, 1996; Morse & Johnson, 1991; Woods, et al., 1993).

The diagnosis of a complex and difficult chronic disease imposes an illness experience of a negative trajectory, a variable illness course, and uncertainty (Corbin & Strauss, 1991; Lazarus & Folkman, 1984; Mishel, 1988; Woods, et al., 1993). These inadvertent proceedings preclude an ample cognitive and emotional appraisal (Lazarus, 1991). One endures a continual temporal uncertainty, with recurrent unpredictable and erratic events, leaving one devoid of a frame of reference to draw personal benefit and advantage (Mishel, 1988; Monat, Averill, & Lazarus, 1972; Penrod, 2001). Suffering for these individuals entails not only the loss of physical stamina, but the personal loss of an anticipated future (Michael, 1996; Morse & Johnson, 1991; Nordenfelt, 1995). Hope and favorable expectations are temporarily lost, placing one in an appraisal situation of continued harm and detriment (Lazarus, 1991; Lazarus & Folkman, 1984; Mishel, 1988; Morse & Penrod, 1991). These collective endeavors impose a susceptible position for the individual to exert personal control. When one is unable to put forth a personal control in a disease or illness situation, there is less ability to assign meaning to the event, making one more vulnerable to distress (Maes, Leventhal, & DeRidder, 1996; Michael, 1996; Stanton, Collins, & Sworowski, 2001; Taylor, 1983). With diminished personal control, coping actions of direct action and vigilance become obscure. This places the individual at a disadvantage to counter a threatening situation with cognitive reframing and they are prone to stressful and emotional reactions (Folkman & Moskowitz, 2004; Lazarus, 1991; Lazarus & Folkman, 1984; Mishel, 1988). Over time this emotional distress hinders fortitude, resulting in one being incapable of integrating disease and illness into their life (Lazarus, 1991; Mishel, 1988; Mishel,

1990; Morse & Johnson, 1991). A graphic representation of these cumulative conceptual links is outlined as follows.

Diagnosis of Complex Disease and the Experience of Chronic Illness

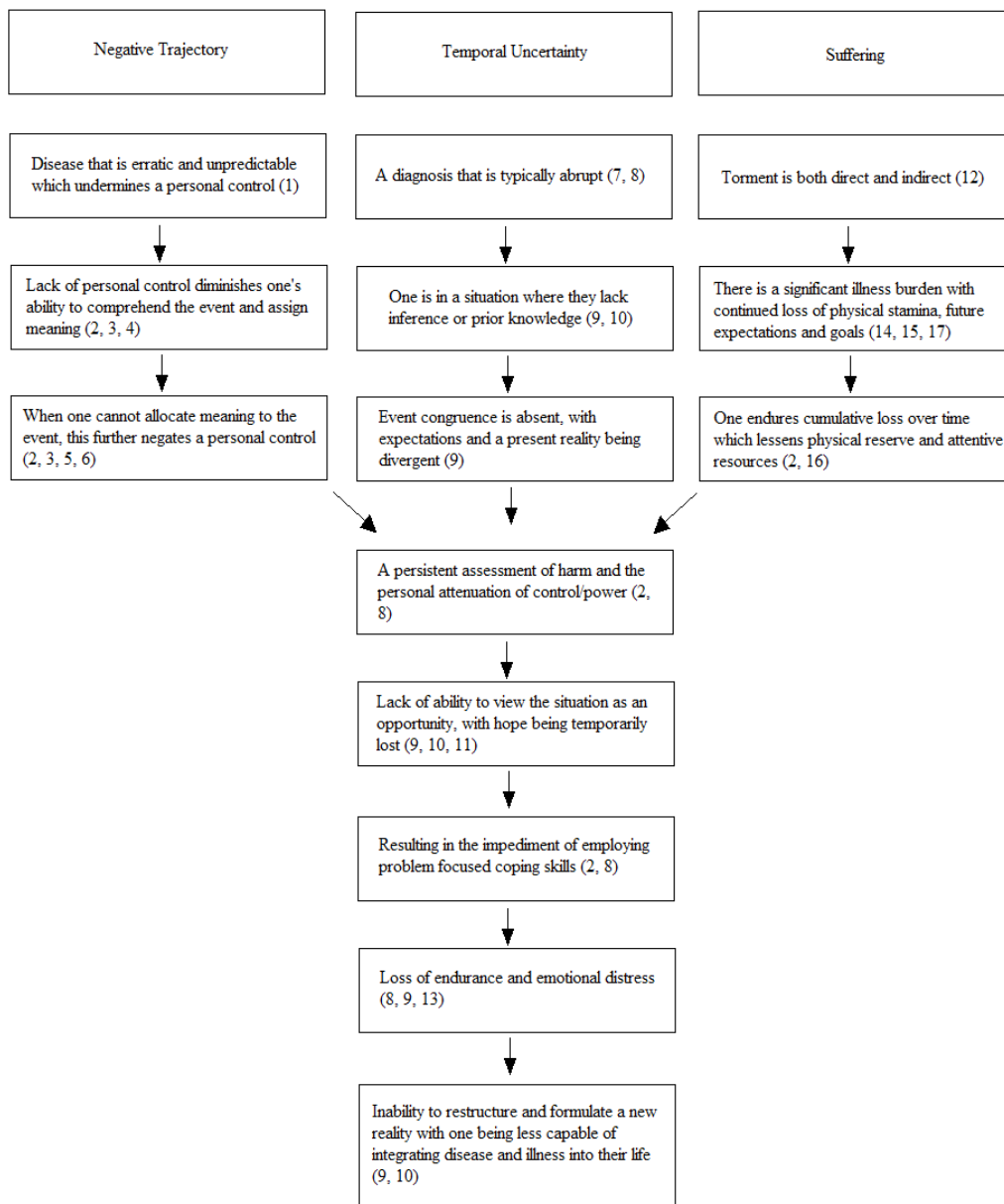


Figure 2. Diagnosis of Complex Disease and the Experience of Chronic Illness.

The references cited for this conceptual map are as follows. (1) Corbin & Strauss, 1991, (2) Lazarus & Folkman, 1984, (3) Maes, Leventhal, & DeRidder, 1996, (4) Folkman & Moskowitz, 2004, (5) Taylor, 1983, (6) Stanton, Collins, & Sworowski, 2001, (7) Monat, Averill, & Lazarus, 1972, (8) Lazarus, 1991, (9) Mishel, 1981, (10) Penrod, 2001, (11) Morse & Penrod, 1999, (12) Nordenfelt, 1995, (13) Woods, et al., 1993, (14) Morse & Johnson, 1991, (15) Michael, 1996 and (16) Taylor, Gibson, & Frank, 2008. Full citations are listed in the reference section of this chapter.

The diagnosis of cirrhosis bears all of the components that have been determined to be difficult for an individual. It is a diagnosis of uncertainty where one is unable to determine the likelihood or timing of physiologic and physical decline (Mishel, 1988; Mishel, 1990, Penrod, 2001). Cirrhosis is an abrupt diagnosis for most, as there are usually no prominent symptoms before the beginning of end stage disease. One is confronted with a negative trajectory that is erratic and unpredictable, leaving little personal control (Corbin & Strauss, 1991). The lack of individual power in serious health situations is a principle influence on non-constructive adaptive outcomes and maladjustment (Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984; Maes, Leventhal, & de Ridder, 1996; Stanton, Collins, & Sworowski, 2001). Additionally, when the measure of incapability exists, the meaning of the situation remains ill-defined (Taylor, 1983). This further negates a personal command and the capacity to engage purposeful behaviors.

The diagnosis of cirrhosis brings the anticipated loss of physical health and the passing of future expectations. It is a diagnosis that marks a reduction in life expectancy, with the average life span of those diagnosed with end stage liver disease being less than 5 years. For those that experience complications related to end stage disease, such as ascites, encephalopathy, or gastro-

intestinal bleeding, these events have the consequence of a 60% one-year mortality rate (Lefton, Rosa, & Cohen, 2009). Suffering for these individuals includes not only the direct physical failing but a personal discerning sentiment that they are experiencing something opposite to their wishes (Nordenfelt, 1995). They are living through the loss of partaking in life as they had expected (Morse & Johnson, 1991). It is a loss that will intensify with a disease progression and further deterioration in liver function. In these situations, where one undergoes increasing loss over time, coping abilities diminish, making personal adjustment and the ability to integrate disease and illness into their life more complex and challenging (Lazarus & Folkman, 1984; Michael, 1996).

With the diagnosis of cirrhosis, one begins the dealings of ongoing surveillance for liver cancer and decompensation. Patient tasks include more frequent outpatient visits, imaging, variceal screening, and lab monitoring. This is coupled with the burden of illness, which is the personal hardship that one undergoes. These private personal demands include concern, worry and apprehension (Woods, et al., 1993). A graphic representation of these conceptual links is outlined as follows.

Diagnosis of Cirrhosis and the Experience of Chronic Illness

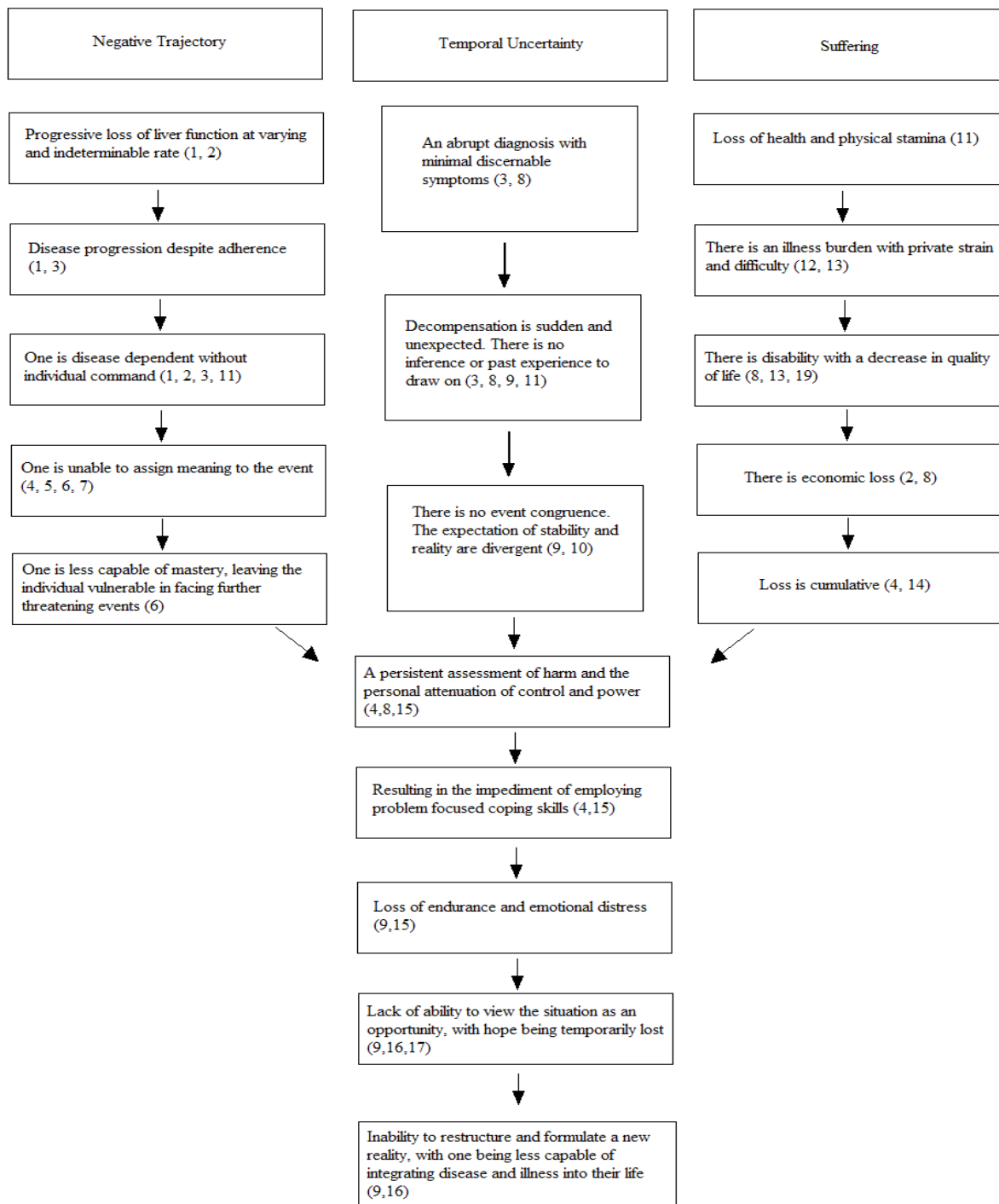


Figure 3. Diagnosis of Cirrhosis and the Experience of Chronic Illness.

The references cited for this conceptual map are as follows. (1) Jarret, 2009, (2) Lefton, Rossa & Cohen, 2009, (3) Gordon, et al., 2012, (4) Lazarus & Folkman, 1984, (5) Maes, Leventhal, & DeRidder, 1996, (6) Taylor, 1983, (7) Stanton, Collins, & Sworowski, 2001, (8) Ge & Runyon, 2013, (9) Mishel, 1981, (10) Tsochatzis, Bosch, & Burroughs, 2012, (11) Ebell, 2006, (12) Neff, Duncan, & Schiff, 2011, (13) Nordenfelt, 1995, (14) Michael, 1996, (15) Lazarus, 1991, (16) Penrod, 2001, (17) Morse & Penrod, 1999, and (18) Taylor, Gibson, & Frank, 2008. Full citations are listed in the reference section of this chapter.

It has been proposed that the aspects of disease and illness produce considerable turmoil and personal disorder in the early post diagnostic phase (Corbin & Strauss, 1991; Woods, et al., 1993). This situation would be intensified when the diagnosis is that of a life limiting disease, such as cirrhosis. During this the individual is responding to a stressful encounter by first assessing the impact of harm. This is followed by a secondary appraisal, where the individual measures their capacity to manage or control the situation (Lazarus, 1991; Lazarus & Folkman, 1984; Selye, 1978).

It is suggested that with health care providers developing knowledge and understanding of the personal impact of a difficult and demanding diagnosis, better care management paths can be established. Although the disease itself may have an unimpeded direction, it is with the timely interventions of nursing care and skill that an illness course can be persuaded to one having the skills to maintain a personal power, employ directed behaviors, and preserve their connection with others. These nursing interventions include empathetic communication, the understanding of another's life position, assisting one to preserve control where possible, teaching, and counseling (Corbin & Strauss, 1991; Lazarus, 1991; Nordenfelt, 1995; Woods, et al., 1993;).

The following segment of this literature review examines the concept of transition, with the prominent work of Meleis. This part includes her theoretical work and the nursing research that tested her middle range theory. The section is concluded with the alignment of the concepts of chronic illness and transition points in care, specifically with the diagnosis of cirrhosis. The chapter is closed with the specific nursing research question to be investigated in this dissertation.

Transitions

As one moves through the course of life, there are continual troublesome and demanding experiences that abate an underlying order in one's life (Levinson, 1986). These changes require one to develop new networks of relationships and a new way of seeing oneself (Schlossberg, 1981). Central to any transition in life is the element of change and difference (Bridges, 1980; Schumacher & Meleis, 1994). Change and difference are not interchangeable terms. Change is the abrupt external event. It is this change occurrence that causes the transition process. During the transition process, there is a personal inner course of action where one begins to let go of the old and moves forward toward a new beginning. The end result of this process is an internal personal difference (Meleis, Sawyer, Im, Messias, & Shumacher, 2000). One is transformed with this private and personal internal engagement and emerges being able to accept the new versus attempting to preserve the old (Bridges, 1980; Kralik, Visentin, & Van Loon, 2006; Schlossberg, 1981).

Meleis and Trangenstein (1994) proposed that the perspective of life transitions are a fundamental concept for the profession of nursing. They put forward the assertion that the exclusive contribution of nursing is defined as the facilitation of patient transitions toward health

and a perception of well being. This goal is accomplished through the process of nursing care and caring.

Within a nursing context, the concept of transition can be differentiated from the global concept of change. Change is an external process which may or may not have flow and direction and could be a brief experience. This is in contrast to a transition process, which involves a progression of change over time and is accompanied with a personal internal engagement (Shumacher & Meleis, 1994). Distinguishing between these two concepts permits insight into specific pertinent aspects of the patient's experience with a troublesome event and a transition process (Chick & Meleis, 1986). The theoretical framework on transitions developed by Meleis was based on three major works. Those works include Blumer's contributions on symbolic interactionism, the ethnographic work of Van Gennep on rites of passage and the work of Bridges, who delineated the key processes of transitions (Blumer, 1969; Bridges, 1980; VanGennep, 1960). Each of these frameworks is addressed in the following section.

The basic premise of symbolic interactionism is that people attach meaning to objects, behaviors, themselves, and others. Human beings are social beings and they are inseparable from their environment and social interaction. Behavior is not solely determined by forces within human beings such as instincts, but rather it is established from a thoughtful interpretation of the event and this analysis incorporates a social perception (Fine, 1993; Howard, 2000).

Blumer (1969) identified three principles, which depict the foundation of symbolic interactionism. First, he proposed that human beings act toward things on the basis of the meaning that things have for them. Secondly, the meaning that one attaches to things is derived from, or arises out of, the social interaction that one has with others. His last contention is that

the meaning that one attaches to a thing or event is modified through an interpretive process used by the individual to deal with what one encounters in life.

From these principled ideas, the importance of meaning is central and it has been identified as the fundamental tenet of symbolic interactionism (Burbank & Martins, 2009). It is within this capability to attach meaning to an event that human beings have control over a situation, and initiate a response, versus being a direct reactor (Blumer, 1969). The meaning that one attaches toward things is influenced by the interaction that one has with both self and others. Self interaction is one's internal conversation and is tantamount to thinking (Blumer, 1966). Meaning derived from social interaction is a learned process, where the actions of others serve to define things for the individual. These reference groups serve as a framework to define a personal perception (Burbank & Martins, 2009).

In symbolic interactionism, human beings are viewed as active beings in relation to their environments and are not passive, conditioned respondents to events (Blumer, 1969). Humans are dynamically involved in what they do, giving them a great degree of control over circumstances (Burbank & Martins, 2009). This perspective proposes that the self is dynamic and human action is comprised of an ongoing process of interaction with one's self as well as interaction with others (Fine, 1993).

An essential element in the position of symbolic interactionism is symbols, predominately words and language. Symbols are socially created and function to characterize shared meaning among members of a society (Sundin & Fahey, 2008). Interaction occurs through the use of symbols and begins with interaction with one's self and those within one's reference group or social unit. This interface results in the underpinning for a perspective or

point of view that guides the individual to interpret the present situation. One then bases their action on this viewpoint and the meaning of this condition. After the action is completed, the effects of this action are interpreted and given meaning. This interpretation of the situation can amend one's explanation of the situation. It is this changed perspective that influences future actions of the individual (Burbank & Martins, 2009; Howard, 2000).

Symbolic interactionism examined the preconditions of self-determination and initiated an explanation for how a vigorous human being is able to overcome forces that the environment emits upon him or her. One's actions are determined by the individual's interpretation and synthesis of meaning from a variety of sources. An individual ultimately forms his or her own action rather than being a reserved witness to the physical environment. The uniqueness of one's response to an event is attributed to the meaning that one has attached to that occurrence (Sundin & Fahey, 2008). Individuals, over time and throughout life, acquire new meanings and action patterns based on changing social interactions (Burbank & Martins, 2009; Howard, 2000).

Meleis (2007) aligns her theoretical framework with symbolic interactionism in two major areas; that of human connection and communication and secondly in the significance of meaning for the individual. Human connection and communication are both elements that are considered to be significant components in the achievement of mastery in a new situation. It is through these dynamic processes of interaction and communication with others that one is able to ascertain significance. In major transition events, one is confronted with the difficult task of executing a role that demands new behaviors and skills. It is with the support of significant others that mastery in a new situation is facilitated. Self assurance is in part realized by being able to reference oneself with others (Blumer, 1969; Meleis, 1975).

The second area of Meleis's work that parallels with symbolic interactionism is to distinguish the significance of meaning for an individual. Meaning constitutes more than a subjective appraisal of an event. It incorporates an existential connection to others which not only serves to create meaning for the individual, but can influence changing that meaning (Blumer, 1969; Burbank & Martins, 2009; Fine, 1993; Meleis, 1975). Being cognizant of this human position allows a deeper appreciation of the conditions that either help or hinder an outcome that is positive for an individual who is undergoing a stressful life transition (Chick & Meleis, 1986; Schumacher & Meleis, 1994).

The ethnographic work of Van Gennep (1960) influenced Meleis in the definition of the fundamental processes that individuals experience in a transition situation. The purpose of Van Gennep's (1960) research work was to develop a theoretical framework to better understand the dynamics and purpose of specific native traditions related to certain points in human development. Portrayed in his work is the observation of four major life transitions in primitive cultures. Those four periods include birth, adolescent rites of initiation, marriage, and funerals. Within each of these times there is a paradox of both letting go and beginning anew, where individuals move from a state of dependency to one of self reliance.

At each of these life transition points, there is an emphasis on tribal customs and traditions within indigenous societies that serve to facilitate these life changes and adjustments. The underlying objective of all customary practices that were observed was to enable the individual to pass from one defined position to another equally defined position within that civilization. The constants throughout Van Gennep's work (1960), irrespective of the society observed, included three categories of developmental passage rites. They are the rites of

separation (as in funerals), the rites of incorporation (as in marriage) and transition rites, which are included in all of the major cultural life transitions.

Although the process of transition is a personal initiative, it is within the formal rites of passage and practice that the social order executes, which smooth the progress for the individual to complete the transition process. There is attestation that a transition process is complete when one is able to move to the more ambiguous role with a deeper sense of identity and relationship with other members of the society. This work opposed the contemporary view at that time, which proposed that human development favored a mechanistic analysis of major processes where a life cycle change shaped the outcome. Van Gennep (1960) did not support this linear course. He asserted that the experience of human development in specific life stages is composed of periods of intense change and chaos balanced with cycles of stability. During these times, it is the external affirmations that a society maintains which promote this internal personal change.

In applying this work to major health-illness transitions there are pertinent themes that are embedded in Meleis' middle range theory. They include the conceptual foundation for the transition process in major life events. These processes include an ending, a beginning and the need for time to absorb the change. Additionally, transition processes are delineated as periods between two fairly stable states with a personal passage or movement between those positions (Schumacher & Meleis, 1994; VanGenupe, 1960).

The process of any major health-illness transition involves an ending of life as one has known it, facing a new beginning and an internal process where one engages a personal course of action. This personal internal action occurs slowly and gradually. Although there is an intimidation of what will be different, the resonance of one's spirit comes when one has had the

time to grasp the change and emerge from an inner disorder and confusion with renewed energy. It is in understanding these critical conceptual pieces that nursing is able to implement appropriate measures of patient support, which can afford a less disturbing process for the individual (Schumacher & Meleis, 1994).

The transition process articulated by Bridges (1980) was a foremost influence for Meleis and the development of her middle range theory for nursing (Chick & Meleis, 1986). Bridges (1980) had two major influences in his work. The first was the work of Van Gennep (1960) and this was in two areas. Van Gennep (1960) articulated and identified the pertinent themes of an ending and a beginning with major life events. The second was in his focus on the need for time in key life transitions in order for the slow and gradual process of an internal identification and engagement to occur. The subsequent shaping event in Bridges' (1980) work was within his own clinical practice. As a clinical psychologist, he worked with individuals who were recently divorced or separated. During this work, he began to observe that with each of his patients' experiences there were underlying commonalities. These similarities included an initial ending of a relationship, followed by a period of confusion and distress. This period of turmoil lead to a new beginning and the recovery of stability in one's life.

Bridges (1980) identified the key elements of the transition process as an ending, a beginning and a period in-between, which is marked with mayhem, loneliness, and emptiness. He presents the consideration that the mechanistic view of change, which proposed that with a time period alone one can adjust to the change, is inadequate in understanding the process of difficult life transitions. The process of transition involves both letting go of the old and finding the new. It is marked by an in-between place that is outside the margins of one's ordinary life. It

is within this non-place that the passage from old to new takes place and a critical inner change occurs.

Transitions begin with an ending or loss and Bridges (1980) directs attention to the opinion that it is not the new beginning that is daunting, but rather the termination of the old. He describes the ending processes as a loss of a former identity. It is a period where one is separated from their previous self or situation and finds themselves in an indeterminate state. There is an inner confusion about the future and a period of neutrality where one endures the loss. It is in bearing through this inner chaos that one is able to attain an inner realignment and emerges with the energy to begin a self reintegration. Although external events may precipitate a new beginning, it is within this internal process and transformation that an individual undergoes which marks the durable and resilient beginning, which the author defines as a successful transition.

Bridges (2009) further developed his initial work on the transition process by applying the model to the wide ranging changes that organizations make. With this broader application of his theoretical work, relevant themes remained constant. The two most demanding aspects of the transition process continue to be in the ending and the neutral zone. In the phase of “an ending and letting go” (Bridges, 1990, p.65), one needs to recognize that a future life trajectory is going to be different. As one goes through the neutral zone, the ambiguities that one experiences can be polarizing. One wants to hold on to what is familiar while trying desperately to push forward. Essential within this time, for a successful transition process to occur, is a pause. This is the time where one can let the old way die, while acquiring the energy and strength for an inner re-orientation and re-definition. It is within these actions that a new beginning transpires.

The more contemporary works of Hogan, Morse, and Tason (1996), and Kralik, Visentin, and Van Loon (2006) closely support the tenets of Bridges (1980) and his depiction of the transition process. The experiential theory of bereavement, (Hogan, Morse, & Tason, 1996), illustrates the phases of bereavement that one undergoes when bearing an extreme life loss. As one endures through the period of intense suffering and despair, there is a point where one comes to terms with letting go while simultaneously attempting to maintain a present engagement and future stance. This intense personal struggle is a central passage, where one emerges with the ability to move on with life. The new beginning includes a personal growth and the power to find meaning in the situation.

Kralik, Visentin, and Van Loon (2006) conducted a literature review on the concept of transition in order to better define the complicated passage of change that an individual undergoes when responding to a disruptive life event. The review determined that there are common, fundamental elements in the process of transition. The transition process entails a change with a concurrent psychological process that serves one in adapting to the taxing event. An essential element of transition is time. Within a transition event there is an ending, then a beginning with an empty time in between where an individual endures dislocation, disorientation, and disorder.

In the work done by Kralik, Visentin, and Van Loon (2006), there is consensus that major life transitions have an ending and a beginning. Their work contributed to the further definition of the internal central elements of the transition process. Life transitions are an intricate and convoluted personal cyclic process, where an individual may move back and forth within the course of the event. This period is not time bound. The additional finding in this work was with the loss of one's self-assurance and identity that occurs in the transition process. This shortfall

makes the connection and the relationships that one has with others an essential part of a successful transition.

Meleis employed the work of Bridges (1980) as a major cornerstone in her theoretical development of the concept of transitions for the profession of nursing. She established that the universal property of the phenomenon was the process of a personal modification over time. Transition was distinguished from change. Change is the external process which may be a short-lived occurrence. Transition involves a progression of a private transformation over time, which is accompanied by an internal course of action, where one emerges from the process distinct and different. There are influencing conditions that affect the transition process and they include meaning, expectation, knowledge, time to plan, and emotional and physical well being. Her work details the indicators of a healthy transition as distress being replaced with a sense of well-being, competence and comfort in the new situation, and the ability for one to maintain relationships with significant others (Chick & Meleis, 1986; Schumacher & Meleis, 1994).

The middle range theory of transition began with the earlier work of Meleis, (1975), where her interest was in understanding the process of mastering new parenting roles and developing nursing interventions that would affect positive healthy outcomes. During this time, she developed the role supplementation theory, which served as a nursing therapeutic when there was an assessment of role insufficiency. She outlined strategies that would promote effective role mastery, with the underlying tenet of communication as being the main process that would make any intervention successful. Although her theory was used as a nursing therapeutic and in a number of research studies, the area in the nature of transitions and the human experience of

transitions continued to surface, which was a concept that Meleis found to be not well defined or understood (Meleis, 2007).

As definitions of nursing matured and began to include the role of nursing as dealing with the human processes and experiences related to health and illness, Meleis (2007), went back to some of her original work with role supplementation. In this work, transitions were identified as an antecedent to role insufficiency, especially when transitions were unhealthy or ineffective. She articulated in her original work that healthy transitions were the goal, and further defined healthy transitions as a mastery of behaviors which are needed in order to assume a new role.

Her new work began with a concept analysis of transition utilizing the framework outlined by Wilson (Rogers & Knafl, 2000). From this concept analysis process, a conceptual definition evolved. Transitions were defined as periods between two fairly stable states and involve a passage or movement between those states. This process was equated with linking change and the occurrence of time. The element of time suggested phases and sequences where the individual experienced an ongoing phenomenon. This initial work became the foundation for the development of Meleis' middle range theory (Chick & Meleis, 1986; Meleis & Trangenstein, 1994).

There are four domains which are included in Meleis' theory of transitions for nursing. These included the nature of transitions, facilitators and inhibitors of the transition experience, patterns of response, and nursing therapeutics. Each of these domains will be addressed in the following sections.

The nature of transitions in Meleis' theoretical framework includes types of transitions, patterns of transitions, and specific properties that are associated with the transition experience.

Meleis identified four types of transitions that are relevant to nursing. These include developmental, situational, organizational, and health-illness transitions. Developmental transitions are equated with a life cycle change or a change in one's relationship with another. Situational transitions are conceptualized as role and educational changes, modifications in one's career over time, and specific family circumstances. Organizational transitions represent those transitions that occur in the environment, which can be triggered by the influence of the more extensive social, political, or economic milieu. Health-illness transitions ensue as a result of either an acute health event, a chronic condition that changes over time, or in the recovery process from a physical or emotional malady (Schumacher & Meleis, 1994).

Transition experiences have certain patterns and incorporate single events, multiple proceedings, sequential actions and simultaneous dealings along with related or unrelated activities. Single and related transitions are considered to be less overwhelming than those transitions that are numerous, concurrent, or divergent (Davies, 2005). In each of these situations, it is the complexity of the event and the parallel effect that one transition occurrence has on another that is relevant (Schumacher, Jones, & Meleis, 1999).

There are five critical attributes that are associated with the transition experience. These are awareness, engagement, change and difference, time span, and critical points (Davies, 2005). The attribute of awareness is related to the perception and knowledge of a transition process. The level of one's awareness is a defining moment in transition. Without the appreciation of a changing event, there cannot be a transition. Engagement is equated with the degree to which the individual is involved in the processes inherent in a transition. It is equated with one's

involvement in the process. This is a proactive stage and includes behaviors of information seeking, preparation, and modification of activities (Marineau, 2005; Meleis et al., 2000).

Change and difference are essential properties of transition and although similar, these properties are not interchangeable. Transition extends the concept of change. Change can be defined as more abrupt and temporary, with transition encompassing a process of change over time. Difference is delineated as one's expectations and includes both positive events, as well as opposing or unmet expectations. This term includes feeling different, being perceived as different, or seeing others in a different way (Marineau, 2005).

All transitions occur over time with an eventual end point and period of stability. The time span of the transition influences the degree of instability, disconnectedness, and adjustment. Those transitions that occur over a longer term would incur greater flux and disorder (Meleis, et al., 2000). The final aspect of the transition is critical turning points and events, which are periods of vulnerability for an individual. This is the time when one has an increased awareness of change or difference, and has a more active engagement in dealing with the experience (Marineau, 2005).

Important characteristics of transition conditions that shape a transition experience include personal meaning, one's outlook, expertise, the environment, the benefit of time to plan, and the advantage of preserved emotional and physical well-being (Schumacher & Meleis, 1994). Meaning is equated with the subjective appraisal of the event and the evaluation of its likely effect. One's outlook is another subjective phenomenon that influences transition and is influenced by previous experience. It is the frame of reference for the individual. When one knows what to expect, the stress associated with the transition may be lessened. A level of

knowledge and skill is necessary to influence a positive transition and if there is insufficiency in this area, one may be unable to meet the demands of the new situation.

The environment plays an important role in transition, with the external resources of family, friends, and social support being considered imperative. Effective planning is another condition that influences success in transition and includes comprehensive problem identification with ongoing assessment and evaluation. Emotional and physical well-being is the final component of the necessary conditions of transitions. This is where one needs to be cognizant of the wide range of negative emotions and physical discomforts that one encounters with unplanned negative change, and how those issues can impede smooth transitions (Meleis, 2007; Schumacher & Meleis, 1994).

In discussing patterns of response, Meleis articulates that transition is both a process and an outcome (Chick & Meleis, 1986). Although this statement seems ambiguous, what the theorist is drawing attention to is both the process of the personal internal modification and the individual end result of that altering life event. One's response to a transitional event is influenced by personal connection with others, being positioned to draw from past experience in order to create new meaning, and having the ability to realize self confidence. These factors influence a transition outcome. Markers that are recognized as healthy transitions include subjective well-being, role mastery, and the well-being of relationships. Subjective well-being involves a sense of dignity and personal integrity. Role mastery denotes achievement of a skill and comfort with the new situation. Well-being in one's relationships is associated with restoration and enhancement in one's connection with others, after a period of stress (Meleis, et al., 2000; Schumacher & Meleis, 1994).

The final section of Meleis' conceptual framework is nursing measures, which are identified in the model as nursing therapeutics. The domains of nursing therapeutics are broadly defined as nursing actions that are either promotive, preventive, or intervening (Schumacher & Meleis, 1994). Promotive actions include assessment skills, patient education, engaging patient support, and diminishing barriers that would detract from a beneficial outcome. Preventive nursing interventions address physiologic stability and the ongoing appraisal of the individual's response and capacity to balance both positive and negative events within one's life. Intervening nursing therapies are those purposeful and directed professional actions that allow for something more for the individual (Gould, 1981; Schumacher & Meleis, 1994). These actions would include the intervention of teaching, counseling, and planning (Corbin & Strauss, 1991).

Meleis' (1997) viewpoint on transitions is that these are more than life events. These are markers that require an intense process of change in oneself. Major life transitions involve changes in self identity, patterns of daily living, and the structure of one's life. Meleis constructed a model that outlines the essential components and processes of critical events that prompt key life transitions. The design of Meleis' transition theory has provided nursing with a cognitive diagram to frame professional action according to the clinical event at hand.

Over the next six years, this framework was tested in practice and findings from these research studies were utilized to uncover any emerging components that had not been identified in the initial work. The research studies that utilized Meleis' framework were representative of susceptible populations that were experiencing transition during vulnerable life situations. These works include the work of Meleis et al., (1996), Shaul, (1997), Robinson, et al., (1997), Im & Meleis (1999), and Schumacher, Jones, & Meleis (1999). From their collective research work an

expanded theoretical framework materialized and included the six concepts of the theory with relationships between the concepts identified (Meleis, et al., 2000). This preliminary research work with Meleis' theoretical model will be discussed in the following section.

Research Literature: Meleis' Emerging Middle Range Theory

Meleis et al., (1996) continued with research work pertaining to life situational transitions in a qualitative study that explored the lived experiences of Mexican women in the work force. This situation of Mexican women in the work force challenged traditional Mexican role generalizations of males being the exclusive provider and females as managers of household. Forty-one female study participants took part in structured interviews. Three themes emerged from this process and they were identified as the centrality of family, a sense of value and empowerment of the women themselves, and the reality of role overload with resulting health implications.

The central importance of family was innermost with study participants, to the degree that family responsibilities always took precedence over work commitments. The themes of value and empowerment were of particular interest to the researchers. In this study, women expressed feelings of fulfillment and an enhanced self esteem. Participants in this study conveyed feelings of being appreciated, having spousal deference and support, while continuing to draw pleasure and contentment from their children. These findings portray support for those aspects of the Mexican culture that accentuate the male's role in valuing and supporting their spouses, versus a contrary opinion of male dominance. Additionally, these findings refute the myth that Mexican women are satisfied with a pre-determined cultural role of being confined to the home, and thus subordinate and dependent on male counterparts. The final theme of role

overload was equated with stress. Although this is not a new or novel finding, attention is drawn to the strict traditional divisions in roles and how these cultural norms can hamper a role transition (Meleis, et al., 1996).

There are two important contributions from this work. The first is in to dismantle critical and judgmental falsehoods about an ethnic group. The second contribution with this work is in providing supplementary information for Meleis' transition theory model. Mexican women in the workforce who participated in this study were undergoing a life situational transition, where traditional roles were challenged by stark economic realities, requiring women to become a part of the workforce. Conditions that influenced an outcome in this situational transition included cultural beliefs and attitudes. These influences can serve to either amend a transition or impede progress toward a healthy standpoint. It is with an awareness of transition situations that pose challenge and encumbrance to another that nursing attention can adjust a response pattern.

Shaul (1997) conducted a grounded theory study with individuals who were diagnosed with rheumatoid arthritis. The objective of the study was to investigate those enduring a chronic illness that has many exacerbations and remissions over the course of one's life and to utilize Meleis's middle range theory of transition as a framework for the study. The study consisted of 30 women who participated in structured interviews. Demographic information was reported as the mean age for the sample was 54 years old, mean duration of disease was 9 years, the majority of participants were married (63%) and all women reported at least two negative changes in physical, psychological, social, or economic function with their disease.

The women in this sample described their experience of living with rheumatoid arthritis in overlapping and recurring stages. Shaul (1997) labeled these stages as becoming aware,

getting care, learning to live with it, and mastery. These stages closely support properties, conditions, responses, and outcomes outlined in Meleis' middle range theory (Schumacher & Meleis, 1994). Becoming aware and getting care were behaviors that aligned with the properties of a transition experience identified as awareness and perception. As individuals began to live with the disease, this stage was associated with an intense personal isolation and loneliness. These conditions had a negative impact and could have potentially inhibited a healthy transition. Patterns of response that emerged from this study were listening to the body, keeping a positive attitude, asking for help, and pretending to be healthy. Mastery was the final stage of the transition process where these women could incorporate the disease and symptoms into their everyday life. This mastery included the ability to achieve a level of skilled insight in order to cope with symptoms and maintain life roles.

The most important finding in this study was that living with a debilitating chronic disease is a major life event that includes a significant personal loss, change in lifestyle, and varying degrees of physical and psychological suffering, all of which produce stress and a variety of coping strategies. An added dimension to the transition model from this work is the concept of time, specifically in a disease with a great deal of uncertainty. One can reach a temporary period of stability, where a steady state can be randomly disrupted by a disease flare. Because time is an essential element of the transition process, Shaul (1997) suggested measuring pertinent variables at specific time points in a health-illness transition process that is variable and inconsistent. This information would enable a deeper understanding of the experience of those who are afflicted with health events that are erratic and beyond one's control.

In a qualitative study, Robinson et al., (1997) wanted to gain an enhanced appreciation of the needs and experiences of individuals who are afflicted with a disease process that has a course of advanced complexity and impediment. Memory loss is a disease process that occurs over time with a movement toward greater difficulty in both the disease process and the illness experience. Meleis' transition theory was utilized as a framework for this study. The study objective was to acquire a better understanding of the experiences of those who are facing early memory loss. A phenomenological approach was employed in order to capture the early experience of memory loss from the perspective of those afflicted.

The criteria for inclusion in this study was that individuals had to be under 65 years old, reported symptoms of early memory loss that had interfered with daily functioning for more than six months, and have not yet been diagnosed with dementia. Eight individuals consisting of three males and five women were interviewed. Two themes emerged from the data analysis, which included the awareness that something was wrong and individual response patterns. Awareness that something was wrong was what participants described as the subtle changes over time that affected their personality, work, and daily activities. Patterns of response were those actions and responsive efforts that individuals used initially to prevent others from recognizing their situation, and later were those decisive actions that sought professional help. These two themes of awareness and patterns of response support Meleis' theoretical framework. Awareness is identified as a property of transition and patterns of response are acknowledged as indicators of progress and outcomes (Schumacher & Meleis, 1994).

Because the recurring themes showed movement over time from a stable state of affairs toward a disordered certainty, the concept of transition was further analyzed with specific

attention on what the individual experiences before seeking professional help (Robinson et al., 1997). Suffering in silence was identified as the overall organizing theme where participants conveyed the feelings of uncertainty and unsettlement that they kept to themselves. An important contribution from this work was the recognition of suffering that these individuals endured. The researchers distinguished that this suffering involved not only a loss of personal control, but the loss of a personal integrity. The theme of suffering provided valuable information at certain time points in a health-illness transition experience, where conditions that were linked to inhibiting health would be assessed. It then became possible for nursing to gain insight into how the transition was proceeding, and to plan for interventions that would assist the patient during the process (Schumacher & Meleis, 1994).

Im and Meleis (1999) studied the specific life change of menopause in Korean women, with findings from their work suggesting further modification in the transition model. The researchers utilized a triangulation methodology. Quantitative analysis was based on data from 119 first generation Korean women. Qualitative data were obtained through theoretical sampling and included 21 study participants.

The mean age of participants was 48 years. The majority of women reported living in the United States for more than 10 years (55%), and most reported being of lower socioeconomic status, with 79% of participants reporting only sufficient or less than sufficient funds. Of these participants, 90% remained married and the study findings reported that the majority of participants held a college education (55%), with the remaining group members reporting no formal education (12%), and those reporting middle or high school education (33%).

Im and Meleis (1999) analyzed qualitative data utilizing a grounded theory approach suggested by Strauss and Corbin (1990). This analysis included coding of interview transcripts, categorizing this data and then describing key relationships between the categories. The three major themes that emerged from this work were that women first minimized negative physical symptoms when more pressing life demands required their attention; secondly, one's culture influences a personal standpoint, and lastly that the women in this study ignored or normalized symptoms that they believed to be transient. The proposal from this work was to amend the transition model in three specific realms. The first was to incorporate the number, seriousness, and priority of transitions with the types of transitions. The second area was to expand transition conditions to include socio-economic status, gender, the inter-relationships among transition conditions, and the individual mind-set toward health and illness. The concluding adjustment that was put forward from this work was to include the assessment of symptom management with indicators of a healthy transition.

This final proposal further characterized the original work of Meleis and Trangenstein (1994), where they recognized skill mastery in a situation as the prevailing attribute in a healthy transition. It is contended in this work by Meleis and Trangenstein (1994), the objective of nursing therapeutics in facilitating healthy transitions is to provide more than immediate control of symptoms. The ultimate target of nursing care is to provide one with the ability to independently manage the situation long term, transcending the immediate event, or circumstances.

Schumacher, Jones, and Meleis (1999) applied the transition model as a framework for gerontological care. Later in life one undergoes multiple transitions which include retirement,

relocation, loss of loved ones and, for most, the onset of chronic disease. The framework offered a logical perspective to convey the degree of complexity involved in health transitions, particularly in the elderly, where there is the resultant need for nursing care that is attentive, inclusive, and enduring. They demonstrated the application of Meleis' transition model with a detailed case study.

From this work, there are three noteworthy contributions to the enhancement of Meleis' theoretical model. These included a more specific definition of patterns of transitions, more detailed identification of the process indicators, and the discussion of explicit nursing therapeutics that have a particular relevance to the aging population. The definition of patterns of transitions was augmented to include those simultaneous events that influence the transition, or sequential events that are caused by the transition. It is with an awareness of the complexity of the situation for the individual, and the ripple effect that one event has on another, that a nursing assessment is more complete. Process indicators that would specifically measure an individual's progress in a transition period would include symptom experience, functional status, a sense of connectedness, a sense of empowerment, and a sense of integrity. Nursing therapeutics that were proposed to assist this population include the requisite nursing assessment, allowing time for one to bridge one stage of life with another by reminiscing, affording one with an awareness of behaviors and goals in the new position, creating environments that were safe and secure, and allocating resources which include personal attributes, family support, and community assets (Schumacher, Jones, & Meleis, 1999).

This collective research work was utilized to enhance the theoretical structure of the transition framework. The enhanced model included the properties of a transition being further

expanded with a more specific definition of patterns within transition. These were labeled simultaneous or sequential events and included number and seriousness of transitions (Im & Meleis, 1999; Schumacher, Jones, & Meleis, 1999). Cultural beliefs, inter-relationships, preparation, knowledge, and socio-economic status were added to transition conditions which would either hinder or facilitate a healthy outcome (Im & Meleis, 1999; Meleis, et al., 1996). The concept of time, awareness, critical points, uncertainty, loss, and suffering were dimensions that were re-articulated, promoting an additional professional awareness for the individual transition experience (Shaul, 1997; Robinson, et al., 1997). Patterns of response that emerged from this work supported the original framework and included the feelings of connection with others and the ability to develop confidence in a new situation (Meleis, et al., 1996; Shaul, 1997). Nursing therapeutics were emphasized and include the directed nursing actions of assessment that encompass all aspects of the transition experience, the allowance for individual time, teaching new behaviors, providing resources, and creating environments that were safe (Im & Meleis, 1999; Meleis, et al., 1996; Robinson et al., 1997; Shaul, 1997; Schumacher, Jones, & Meleis, 1999).

The revised model was then published with direction from Meleis for continued research with the application of her middle range theory in nursing practice (Meleis, et al., 2000). The following includes those works and include the scholarly contributions of Mercer (2004), Shin and White-Trout (2007) and Rossen (2007) and the research initiatives of Messias (2002; 2010), Kralik (2002), Samarasinghe, Fridlund, & Arvidsson (2006), Rossen & Knafl (2007), Rittman, et al.(2007), Weiss, et al. (2007), Ekwall, Ternestedt, & Sorbe (2007), McEwan, et al. (2007), Riegel & Dickson (2008) and Rich (2010), who utilized Meleis's theoretical framework in

situational and health-illness transitions. These published works, which have provided further insight and appreciation on the transition process, demonstrate the usefulness and significance of Meleis' theoretical framework (Peterson & Bedrow, 2009).

Scholarly Contributions: Transitions as a Nursing Theory

Mercer (2004) investigated the development of maternal role attainment and the factors that inhibit or facilitate a healthy transition. Meleis' middle range theory (Meleis, et al., 2000) was utilized as the guiding theoretical framework. Mercer (2004) examined contemporary and relevant theoretical works that depict the processes of maternal role attainment. Those specific qualities include one's personal condition, cultural beliefs, socioeconomic status, preparation, knowledge, and community and societal conditions. Mercer (2004) advocated that becoming a mother encompassed more than the achievement of a maternal identity. The process began with an initial transformation but continued on with persistent growth in the maternal role as the child developed and life stressors contributed to a disorder in role confidence. It is in the understanding of the variables that contribute across the life span of the mother/child relationship that we develop more precise and accurate concept portrayals. This work supports Meleis' theoretical framework on the transition process of motherhood and factors that influence or inhibit a healthy outcome. Mercer (2004) identified the transition to motherhood as a change that takes place over a lifetime and delineates the influencing factors of knowledge, personal relationships, and competing responsibilities as contributing to self reliance in the role of motherhood.

Mothers who experienced infants in NICU presented an opportunity for research in a difficult developmental transition. Shin and White-Trout (2007) found the concept of transition

to motherhood in the NICU to be not well understood and often muddled with a mother's psychological responses to the NICU environment. In order to more accurately define the transition to motherhood with an infant in the NICU, the researchers conducted a concept analysis utilizing the Hybrid model. This model has three components, a theoretical phase, a field work phase and an analytical phase (Rogers & Knafl, 2000).

The initial work began with a literature review on the concept of transition to motherhood with infants in the NICU. From the review of literature, common themes were identified. These included a time process of attachment, the psychological well being of the mother, and maternal role attainment. This phase was followed by field work, where ten mothers with infants in the NICU were recruited and semi-structured interviews were conducted. From these collective findings, three critical attributes were identified. These were the time dependent process of motherhood with a child in the NICU, the psycho-emotional swirling that occurred with mothers of NICU infants, and the feelings of hovering on the edge of mothering that these women experienced.

The results of this work contributed toward a more complete awareness of the factors that influence the transition to motherhood in the NICU setting. These facets include the attribution of negative meaning, uncertainty, social prejudice, the lack of opportunity for maternal social contact with her infant, and the overall unit environment. This work substantiated Meleis' theoretical work on transition theory as applicable for explaining the developmental transition to motherhood with a NICU infant in two major areas of the framework. These are the properties of the transition experience and influencing factors for a healthy outcome. Specifically, the properties of awareness, engagement, change, and time span were all identified as specific

elements in this process and explicit factors that impact a healthy transition to motherhood with an infant in NICU were recognized (Shin & White-Trout, 2007).

In applying Meleis' model to a specific clinical situation, Rossen (2007) proposed a particular nursing assessment for late life situational transitions of relocation. The author constructed two questionnaire tools that could be utilized by nursing to assess individuals who may be at risk for poor adjustment when relocating. The work concentrated on a distinct situational transition of relocation in the elderly. The author proposed that when there is an enhanced patient appraisal for readiness to relocate, nursing is provided with an index to gauge those at high risk for an untoward outcome.

The strength of this work is twofold. The first is in applying Meleis' theory to a specific clinical situation. The second is in the recommendation of employing specific nursing assessment questions to assess individuals prior to relocation. It is proposed that this assessment could identify those in jeopardy of an unfavorable outcome. A limitation to this work is that there is no further published work regarding utilizing these assessment tools in practice. This shortfall leaves the accuracy, stability, and consistency of the tool to be yet determined.

Research Literature: Transitions as a Nursing Theory

In this following section, the research initiatives pertaining only to situational and health illness transitions will be addressed. Research work related to organizational and developmental transitions were not relevant to the research question proposed in this dissertation. Situational transitions will be addressed first and include the topics of immigration (Messias, 2002; 2010), relocation (Samarasinghe, Fridlund, & Arvidsson, 2006; Rossen & Knaf1, 2007), discharge from acute care (Rittman, et al., 2007) and readiness for discharge (Weiss, et al., 2007).

Messias (2002) asserted that a transnational health perspective is an important context for nursing to investigate, in order to more fully comprehend ethnic health practices. The researcher designed a qualitative study where 26 immigrant Brazilian women told their stories of immigration and their health perspectives, practices, and resources. The purpose of this study was to examine a significant life situational transition and to explore the health perspectives, practices, and resources of immigrant women in order to gain knowledge and understanding of the range and extent of the influences of a specific transition situation and health practices.

The study participants were all Brazilian women who had immigrated to the United States. The mean length of residency was 5.9 years, the mean age was reported at 33 years of age, and median age of immigration was 30.5 years old. The participants were diverse with women immigrants reporting backgrounds of both lower and upper middle class, and living in both urban and suburban geographic areas in Brazil. Eighteen of the study participants were married or partnered, with three participants being separated or divorced, and the remaining five individuals were single. The majority of women held a high school diploma with nine having completed a college degree. All but two participants were employed when interviewed for the study. Each of the employed participants reported being employed in lower socioeconomic positions, which included domestic help, babysitting, home health care, or house cleaning.

The result from these interviews was the identification of two themes. The first was transnational resources. A consequence of immigration is that one's identity becomes more fluid. If one is unable to integrate or remains marginalized, there is the propensity to return to what was known about health care practices, leaving some at risk for less than optimal health care. The second theme was crossing multiple borders. Immigration entails crossing borders, which the

study participants described as not only passage through national boundaries but included those restrictions set by language difficulty, cultural dissimilarity, and financial needs.

This work supported two areas in a situational transition. The first is that when a transition outcome of a fluid and integrative identity is not realized, one is less capable to move forward in the situation. This results in one resorting to previous health behaviors which may diminish a productive outcome. The second area of knowledge gained from this work is in sustaining that difficult transitions have processes that are multidirectional, persistent, and repetitive. This insight contributes toward a professional acumen that heightens sensitivity and proficiency in cultural competence and capability in providing directed care initiatives (Messias, 2002; Schumacher, Jones, & Meleis, 1999).

Messias (2010) conducted further theoretical work on the situational transition of immigration with the application of Meleis' transition framework. The work linked the more comprehensive representation of migration to the immigration process, which includes the aspects of multidirectional and frequent movements across geographical locations. Essential contributions from this work lie in refracting a professional focus. The author asserted that it is when the profession of nursing gains knowledge about a complex life transition, and couples this with an appreciation for the pervading conditions that impede a productive outcome, that calculated and responsive nursing interventions can be implemented. In utilizing the transitions framework as a guide, one has the capacity to distinguish the intricate and repeating components of a difficult transition situation. One is able to take into account the array of experiences and changes that arise from one passing through one life situation to another, with the resultant

requirement for the redefinition of self. This awareness ability allows for implementation of nursing interventions that affect more than a standard or uniform outcome.

In investigating the health of those that undergo involuntary situational transitions, Samarasinghe, Fridlaund, & Arvidsson (2006) conducted a phenomenological study to describe the health experience of refugees seeking asylum. The researchers interviewed thirty four refugees who were seeking asylum and data that were analyzed encompassed a number of essential categories. These include the experience of living with uncertainty, managing being misunderstood because of language problems, tolerating societal non-integration, and enduring the effects of grief and sorrow that are both raw and unprocessed. Implications for nursing from this study include the assessment approach of considering the effects of cumulative and collective stressors on health and the need for nursing interventions to concentrate on strengthening identity and roles while simultaneously reducing environmental discord and tension. The authors maintained that stability and healthy function in these life situations are regarded as one having a well-defined role, having the ability to live a worthy life, and being able to live in togetherness with others. The implications and recommendations from this work sustained Meleis's theoretical framework that with encompassing nursing assessments in a significant transition processes, more precise nursing interventions can be executed to construct stable and healthy outcomes.

Research conducted by Rossen and Knafl (2007) maintained a focus on relocation of elder women. Meleis' transitions framework was utilized with the focus being on transition conditions and healthy outcomes. The researchers conducted a mixed methodology study. Self esteem, depression, and quality of life were measured by the Quality of Life Index, at two

relocation time points. Initial testing was prior to the move to an independent community and the second time point was at four months after relocation. Results of these measures showed a significant increase in quality of life post move with 73% of participants reporting greater satisfaction with their socioeconomic status and 81% of participants reporting greater overall life satisfaction. This finding was in contrast to previous work cited by the authors (Rossen & Knafl, 2007), where it was found that relocation can have a negative impact on one's mental and physical health.

Qualitative data identified three thematic patterns which were identified as full integration, partial integration, or minimal integration. These data were then matched to the participant's scores on quantitative measurement tools. Those study participants that reported only partial or minimal integration demonstrated scores of 75% lower on self esteem, 54% lower on quality of life measures, and 8% higher on depression scores. Those individuals who described their experience as full integration all demonstrated high scores on quality of life instruments (100%) and 93% of those individuals had low scores in depressive symptom measures. The initial findings in this study suggest assessment measures for a transition condition in a specific situation, with certain scores and traits as having the potential for less than a beneficial outcome. An inadequacy in this work is that data were collected at only one time point after relocation and further replication of the study was not conducted, making the opportunity to generalize and apply the initial findings problematic.

Rittman et al., (2007) investigated the psychological domains of the transition experiences of stroke victims when discharged to home. The researchers designed a longitudinal mixed methodology study with 125 stroke survivors who were discharged to home. Quantitative

data were collected utilizing four instruments that measured functional status, mental status, depression, and activities of daily living. The quantitative data that measured both functional status and activities of daily living showed evidence of improvement at the one month after discharge measure. Functional status measure improved with 63% of the participants and activities of daily living had improved measures in 53% of participants. However, depression scale measures were high in this study population at the one month post discharge time point, with 63% of participants scoring in the depressed range of measurement.

Qualitative data were obtained from twelve patient interviews and field observations made at the home visits. The domains that emerged from the qualitative data analysis were identified as a change in one's self image, a change in connection with others, and a change in community integration. The most common experience expressed by stroke survivors was the change in self image and personal abilities. The feeling of isolation was a key issue that these individuals faced and this emotion impeded a connection with others. The change in community integration was described as the restrictive levels of activity participation because of physical limitations.

The researchers linked the qualitative domains with quantitative measures and were able to make associations. Higher measures of depressive scores were related to a disruption in ones' sense of self, less than ample social connections, and loneliness, with the implication that these factors would influence a more difficult transition. Data were matched for community integration and quantitative measures of functional skill, depression, and quality of life. Individuals who were able to maintain moderate to high engagement in community activities benefited from a more optimistic future outlook. This is in contrast to those individuals who experienced a more

restrictive life, where results showed evidence of more depressive symptoms and the attitude of being an onlooker to meaningful life activities.

The results of this study put forward that stroke victims who are one month post discharge from acute care are managing multiple changes during a difficult transition period. The researchers defined positive outcomes as continuing to having a purpose in life, maintaining quality connections in one's existence, and being able to master one's environment. Interventions that could promote a healthier transition and improved quality of life included the preservation of connection with loved ones, to maintain individual involvement in community activities, and that caregivers assist both victims and significant others in understanding the change in one's sense of self that occurs after suffering a stroke. These proposed findings, outcomes and interventions aligned closely with Meleis' transition framework in the following areas. These study participants were undergoing a health-illness transition which had multiple patterns and complex conditions that influence a pattern of response. It was with the nursing intervention of support to the individual to maintain a connection with others and assistance for the caregiver that a healthy outcome became more probable (Meleis et al., 2000).

Weiss et al., (2007) investigated the patient characteristics, hospitalization factors, and nursing practices that are predictors of patient readiness for discharge. Hospital discharge was viewed as a transition process occurring at three time points. Those points, where readiness for discharge was investigated, were identified as the hospital phase where discharge preparation occurs, the discharge from acute care, and post discharge when the individual is coping with the demands of home care and their need for support. Meleis' middle range theory on transition was

selected as the guiding theoretical framework with the areas of nature of transitions, transition conditions, nursing therapeutics, and patterns of response explored.

The study design was descriptive and correlational, where the projected relationships between the nature of the transition, the transition condition, nursing therapeutics, and patterns of response were investigated. Hospitalization factors including planned or prior admissions, and length of stay equated with the nature of the transition. Transition conditions were identified as patient characteristics and included factors such as age, race, socio-economic status, insurance, and if the individual lived alone. Nursing therapeutics were recognized as discharge teaching and care coordination. Patterns of response were identified as readiness for hospital discharge, post discharge coping difficulty, and post discharge utilization of health services. The sample consisted of 147 adult medical-surgical patients who participated in the study. Of the study participants, 69 were men and 78 were women. Four measurement tools were utilized to assess for discharge teaching, readiness for hospital discharge, care coordination, and post discharge coping difficulty. Utilization of support and health services was self reported.

A path analysis was developed from regression data analysis. The paths measured were the effects of transition conditions, the nature on transitions, and nursing therapeutics on the patient readiness for hospital discharge. There were three significant findings which could be utilized as predictors of readiness for discharge. Negative predictors included those individuals who lived alone and had poor care coordination. A positive predictor was the quality of the discharge teaching. In the data evaluation of those demonstrating post discharge coping difficulty, the analysis demonstrated the following findings. Younger adults who did not perceive

themselves as ready for discharge had more difficulty in coping, and those experiencing their first admission to the hospital were more likely to have an outpatient unscheduled office visit.

The results of this study validated the importance of skilled quality discharge teaching as the strongest predictor of discharge readiness. This finding is consistent with Meleis' transition model which asserts that the nature of the transition, the transition conditions, and nursing therapeutic action will affect a healthy response during a transition experience.

Research in the area of health illness transitions includes the work in studying women with chronic illness (Kralik, 2002), the experience of women who had recurrence of ovarian cancer (Ekwall, Ternestedt, & Sorbe, 2007), the diagnosis of diabetes (McEwan, et al., 2007) and influencing factors with heart failure patients (Riegel & Dickson, 2008). Each of these works will be addressed in the following section.

Kralik (2002) conducted a qualitative study with midlife women who were living with chronic illness. Over a year time frame, 81 women who identified themselves as having an adult onset of a chronic disease were asked to tell their story about that experience. Participants told their story through a written narrative. These data were then thematically analyzed and presented as a description of the experience of illness.

Two themes emerged from this study: were extra-ordinariness and ordinariness. Extra-ordinariness was conceptually defined as the struggle that follows the crisis event or profound life occurrence. It was a phase of turmoil and overwhelming unpredictability. In confronting life with chronic illness, there was a state of estrangement, where there was grief for the loss of a former self. There was a collapse and disintegration of one's self esteem. Self assurance was

tested with feelings of insecurity, vulnerability, and loss of optimism, where the capability to move forward was absent.

Ordinariness was defined as the phase of re-structuring one's life with illness. This transforming experience was a dynamic state which required a phenomenal personal effort and constant vigilance over thoughts and responses to the experience of living with illness. This phase was the period where one found a place for illness within their lives, achieved by taking calculated risks, temporarily surrendering security, and identifying the necessary changes that need to take place, so that illness could have a position in their lives. Once a sense of ordinariness was achieved, life regained balance and control. There was stability. The disturbing elements of the extra-ordinary phase were relinquished and one has a future direction. In the phase of ordinariness there was a reconstructed identity and a re-birth where one is able to now move on.

The research work of Kralik (2002) supported earlier theoretical work on the concept of transition (Bridges, 1980; Bridges, 2009; Chick & Meleis, 1986; Meleis & Trangenstein, 1994), which purports that change is the impetus for transition. Change is the external process which requires the individual to choose one event over another. Transition is the internal process that occurs over time. Within this process there is flow and movement, with considerable episodes of uncertainty. The process of transition is given further details in this work with the illustration of how individuals begin the transition period and points where one needs to re-shape their personal worlds by adjusting expectations.

Ekwall, Ternstedt, and Sorbe (2007) conducted a phenomenological study where they investigated the lived experience of twelve women who experienced a recurrence of ovarian

cancer. The authors considered this event to be even more devastating than the original diagnosis because treatment which was considered the best chance for a cure had failed. Three main themes emerged from the interviews and these were that one is being denied a future, the feeling of being alienated both from one's self and one's surroundings, and the sense of responsibility that these women felt. This responsibility was apparent in their commitment to healthy lifestyles, maintaining a positive attitude, and protecting those close to them by minimizing disturbing medical information or their personal anxieties.

The three themes that transpired from this study were integrated into a whole structure, which the author's labeled as "living in limbo" (Ekwall, Ternstedt, & Sorbe, 2007, p. 270), where one is on the threshold of the unknown. The concept of health illness transition was applied to the phenomenon of "living in limbo." This connection permitted an extended view of this concept by enhancing the patient state of uncertainty and conflict, to where women in this situation found themselves between two worlds, one of health and one of being ill. The existential loneliness that participants described in their illness passage negatively impacted a healthy transition which was characterized as being connected, confident, attaining mastery, and experiencing a sense of well being. Significant clinical information gained from this study included the feelings of isolation that women experienced with disease recurrence, and the value that these individuals placed on the importance to continue to care for others (Ekwall, Ternstedt, & Sorbe, 2007; Schumacher & Meleis, 1994).

McEwen et al., (2007) designed a mixed methodology study to investigate a health illness transition in Mexican immigrant women with a new diagnosis of diabetes. The researchers utilized Meleis' middle range theory as the theoretical framework for this study. The theory

provided the structural context to comprehend the complex adaptations that immigrant women make as they manage a health illness transition with a chronic disease such as diabetes. The researcher interest was to evaluate an individual's response to a major health-illness transition and factors that facilitate a healthy outcome. The quantitative approach was developed as one group pre-and post-test design with a convenience sample of fifteen participants who had been diagnosed with Type 2 diabetes. Study participants completed a set of self reported questionnaires at two time points over a six-month interval. Initial data were collected at the first group session and the second data set was obtained at the last group session when the intervention of four home nursing teaching visits was completed. Measures implemented were used to compare differences in diabetes knowledge, social support, diabetes related behaviors, and psychological problems.

The results of quantitative data demonstrated significant changes pre- and post-intervention in three of the identified issues of inquiry. Those areas include diabetes knowledge, diabetes related behaviors, and psychological problems. Scores on diabetes knowledge increased significantly post intervention from 16.27 to 18.93 ($p < .001$). Health related behaviors improved after intervention with medication management problems reduced by 53.3%, health care supervision reduced by 33.3%, and nutrition problems reduced by 20%. The women in this study reported a reduction in psychological problems post intervention with problems relating to role change decreasing by 33.3%, a 6.6 % decrease in problems related to interpersonal relationships, and a 20% post intervention decrease in problems related to community resources.

Qualitative data were obtained through focused discussions with the purpose being to augment and complement information on the experience of a new diagnosis of diabetes. These

data produced three themes and these were the difficulty that one has in acknowledging diabetes as being a part of one's life, adjusting to change, and difference and putting family first. All three of these themes are evident in Meleis' transition model. The difficulty that an individual has in acknowledging a chronic condition is associated with identity, awareness, engagement, and time. One's adjustment was associated with change and difference. The final theme of putting family first was related to the healthy outcome of engagement and self management.

The work accomplished in this study extended the theoretical application of the transition model. The results supported the notion that difficult and complicated transitions need time for a personal inner alteration and adjustment. In this work, some individuals who had been previously diagnosed with diabetes took as long as one year to redefine themselves as a person and engage in self management. The researchers suggested that this finding supports a thoughtful modification in nursing educational approaches, where effective long term teaching and self management techniques may not begin with an initial diagnosis. When a health illness transition is persistent and prolonged, teaching strategies need to be highly sensitive to the patient's level of self awareness and ability to engage in self management behaviors (McEwen, et al., 2007).

In order to further explore the conditions of knowledge and skill as influencing factors in a health illness transition in heart failure patients, Riegel and Dickson (2008) utilized a descriptive meta- analysis to assess the self-care skills in patients who have heart failure. Themes were identified from data collected from eighty-five study participants who were involved in three prior studies. Data were re-examined using within study and across study analysis in order to establish a more inclusive and wider ranging comprehension of the development of skill in heart failure self care.

Two themes emerged in this work and these included tactical skill and situational skill.

Tactical skill involved routine behaviors while situational skills involved making decisions about signs and symptoms. With the uncovering of this information, the authors put forward the proposal of a hierarchy of patient skill development, where nursing needs to be ever cognizant of the unique situation of each individual patient. True self-care in patients engages a consistency and coherence in linking symptoms to specific actions in particular situations. Confidence and independent health management, which the authors' define as true self-care, are abilities that evolve over time.

The major strength of this work is the application of Meleis' middle range transition theory to an explicit clinical situation. The results capture the fundamental concepts of time that is needed in transition and factors that influence the positive end result of mastery in a situation. Nursing interventions that would facilitate self-care and mastery are patient skill development (Meleis, et al., 2000; Riegel & Dickson, 2008). This key dimension is further outlined by the researchers and guides the profession with more contemporary teaching strategies that accommodate both tactical and situational skill in complex patient populations. They assert that these approaches will sanction progressive and highly developed patient self care management abilities (Riegel & Dickson, 2008).

Summary

Meleis' theory of transitions proposes that assisting people to manage life transitions is a key function of nursing (Schumacher & Meleis, 1994). Research conducted utilizing the transitions nursing framework has contributed to professional knowledge in two major spheres. Foremost is the substantiation in the capacity of the theoretical model to delineate complex

patient transitions. An equally important outcome is in the nursing research findings in the clinical studies conducted across the domains of the theory. This work has added to the improved and enhanced understanding of the conditions when transition processes occur and where the directed actions of nursing care can actualize a difference for another.

It has been established that transition experiences have identifiable patterns. The complexity of the event and the parallel effect that a transition occurrence has on other aspects of one's life is categorically significant (Kralik, Visentin, & Van Loon, 2006; Schumacher, Jones, & Meleis, 1999). Variables such as involuntary transitions, multifaceted situations and events that encompass overwhelming unpredictability have been designated as incidences that shape the process of a transition where one is at risk for escalating stress and response patterns that are adverse (Samarasinghe, Fridlaund, & Arvidsson, 2006; Schumacher & Meleis, 2009). What continues to be esoteric is the identification of critical periods in various patterns of transitions and aligning this knowledge with nursing interventions that afford response patterns of well being and skill (Meleis, et al., 2000; Schumacher, Jones, & Meleis, 1999).

Characteristics of transitions include the qualities that one is mindful of a change, a personal commitment to the transition process, an individual perception of a future difference or disparity, and the capability for one to traverse precarious turning points and events during the process. With an inclusive perception of these attributes, one becomes more thoughtful on the influence these factors have on healthy outcomes. Specific properties of awareness, engagement, change, and time have been identified as explicit factors that impact the response patterns. When these elements are coupled with uncertainty there is the imminent likelihood of psychological suffering, troublesome stressful responses, and an inability to employ coping strategies (Lazarus,

1991; Mercer, 2004; Mishel, 1988; Selye, 1978; Shaul, 1997; Shin & White-Trout, 2007; Robinson et al., 1997).

Time is a fundamental element in the transition process (Bridges, 1980; Bridges, 2009; Kralik, 2002; Kralik, Visentin, & Van Loon, 2006; VanGennup, 1960). When one is only afforded temporary periods of stability and the disadvantage of not having time for an inner self realignment, that individual is in a position of consequence for untoward outcomes. It has been proposed that research be conducted at specific time points in transition processes that are variable and inconsistent. This information, when ascertained, would draw attention to the individual experience of those who are afflicted with events that are erratic and beyond one's control. This appreciation allows health care providers to direct professional actions of care that afford one more control and conviction in a situation that is indistinct and unclear (Schumacher, Jones, & Meleis, 1999; Shaul, 1997).

Transitions are personal ventures that require an internal identification and engagement. The conditions that influence a transition process include individual meaning, expectations, the ability to plan, and emotional and physical well being (Meleis, 2007). There are a number of factors that are detrimental to a positive transition outcome. These include when the transition is inadvertent, when one cannot reach a fluid integrity, and when the situation is complicated by other parallel and influencing events (Mercer, 2004; Messias, 2010; Rosen & Knafl, 2007; Weiss, et al., 2007). Those who are tasked in confronting these exigent transitions live thorough a wide range of emotional reactions that include fear and sentiment that is unbalanced (Ekwall, Ternstedt, & Sorbe, 2007; Hattar-Pollara, 2010, McEwen, et al., 2007; Shaul, 1997). One endures the effects of cumulative loss, which over time diminishes physical reserve. This loss of

physical well being interferes with assimilation of new information and restrains successful transition outcomes (Schumacher & Meleis, 1994).

Chick & Meleis (1986) convey that a transition experience is both an individual process and an ending result. Markers that have been established in determining a healthy outcome include subjective well being, role mastery, and the well being of relationships (Meleis et al., 2000; Schumacher & Meleis, 1994). It has been proposed that those who have the capability to be more adaptive and assimilate the transition event into their life have the propensity for a less stressful endeavor (Messias, 2002). Role mastery allows one to cope in a new situation by affording one control and allowing for a demonstrative emotive constancy (Lazarus, 1991; Meleis et al., 2000; Selye, 1978; Shaul, 1997; Walker, 2001). In maintaining the well being of relationships, one is both more capable in clarifying the significance and implication of the transition event and more able to continue with purpose and intention in life (Ekwall, Ternstedt, & Sorbe, 2007; Samarasinghe, Fridlaund, & Arvidsson, 2006; Shaul, 1997; Rittman, et al., 2007).

The domains of nursing therapeutics have been broadly defined as being promotive, preventive, and intervening with patient transition events. These interventions are more comprehensive than complex technical skill and include the acts of teaching, counseling, and planning (Corbin & Strauss, 1991). It is with these incisive and directed purposeful professional actions that a more positive outcome in a challenging transition experience can be realized (Schumacher & Meleis, 1994). As there is understanding of the meaning of the event for the individual, a recognition of the significance of the loss for the individual, and an appreciation that one is not only readjusting expectations but restructuring their world, there is an enhanced

potential for a patient relationship that will have more influence for a restorative and healed outcome (McEwan, et al., 2007; Shaul, 1997; Riegel & Dickerson, 2008; Robinson, et al., 1997).

Chronic Illness and Transition Points

Chronic illness has been differentiated as the intense psychological process that an individual experiences, with a disease event and the personal insight and action that proceeds from that occurrence (Conrad, 1990). Those who endure a diagnosis that has an unrelenting and interminable course are at high risk for problematic stress responses, emotional distress and a lack of ability to employ coping strategies (Seyle, 1978; Lazarus, 1991; Shaul, 1997; Robinson et al., 1997; Mercer, 2004; Shin & White- Trout, 2007). These responses leave one in jeopardy of reaching a positive end with a difficult transition occurrence. That affirmative end has been delineated as one undergoing a decisive personal inner change, an individual growth that allows for a capable and resourceful self assurance, maintaining the ability to live a meaningful life and the preservation of a connection with others (Bridges, 1980; Chick & Meleis, 1986; Meleis, 1975; Samarasinghe, Fridland, & Arvidsson, 2006; Schumacher & Meleis, 1994).

Research findings have suggested that aspects of an illness and disease symptoms produce greater personal disorder in the early and late stages of the disease (Woods, et al., 1993). One's initial response to diagnosis has an essential implication for health care providers. It is in this primary estimation of the incident that shapes forthcoming actions and ambitions (Folkman & Moskowitz, 2004; Leventhal, Leventhal, & Breland, 2011). This initial cognitive assessment and emotional response directs imminent coping behaviors (Lazarus, 1991). These research findings maintain that future study in a health illness transition be investigated in the early post diagnostic phase. This would permit health care providers a more comprehensive understanding

the chronic illness experience and sanction interventions that would influence coping and adaption (Corbin & Strauus, 1991; Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984; Stanton, Collins, & Swordkowski, 2001; Taylor, 1983).

With chronic illness, one is not afforded the comfort of regained wellness. This occurrence detracts from an individual securing a continued control and influence with the situation (Morse & Johnson, 1991). When one perceives a situation to be irrepressible, they bear the likely forthcoming effects of being unable to engage higher level coping skills. These skills include an intellectual and rational deliberation where problem solving, information seeking and problem focused coping skills are engaged and allow one to employ a personal power in the present situation. This control contributes to stress regulation, healthier adjustments and individual adaption (Folkman & Moskowitz, 2000; Lazarus, 1991; Lazarus and Folkman, 1984; Seleye, 1978; Stanton, Collins, & Sworowski, 2001; Stuijbergen, Seraphine, & Roberts, 2000).

In a chronic health illness transitions, one is challenged by an external event that requires the individual to undertake a decisive personal internal process that results in a change over time in one's future presumptions, behaviors and relationships. One accustoms and adapts to the situation by developing new behavior responses and avoids the enticement of reverting to a preceding and contented state (Bridges, 1980). What is essential for one to emerge successfully from this inner turmoil is time. It is within this personal pause and respite that one is able to let go of the old, while simultaneously acquiring the energy and stamina for an inner re-alignment and modification of one's position (Bridges, 1980; Bridges, 1990; Schumacher & Meleis, 1994; VanGennup, 1960). This critical point in the transition process, when an individual is able to suppress old and contradictory suppositions and be open to new experiences and thoughts, is the

demarcation of a successful transition. It is where one emerges with the capability for a keen and earnest new beginning (Bridges, 1980).

The diagnosis of a chronic condition requires a physical, social and psychological adjustment and this is most pronounced in those that have the misfortune of a protracted diagnosis (Thorne, 1998). Cirrhosis is a diagnosis that indicates a central change in the focus of patient care with chronic liver disease. It marks a point when one transitions from a secure point in illness and to one that is defined as end stage (Tsochatzis, Bosh, & Burroughs, 2012). This diagnosis is marked with uncertainty, a negative implication and an illness trajectory that is inconsistent and contradictory (Jarrett, 2009). It has been proposed that in developing a deeper understanding of the distress and difficulty associated with the onset of a diagnosis that is linked with long term detrimental and injurious effects we enhance our ability to care for individuals and steer outcomes that are both constructive and beneficial (Corbin & Strauss, 1991; Woods, et al., 1993).

To date there have been no studies conducted on the experience of individuals who endure the diagnosis of cirrhosis and the aftermath of this diagnosis. This marks an important deficiency in knowledge for a specific patient population that is undergoing a significant health illness transition. It is in gaining an enhanced understanding of what remains unidentified that we develop the ability to become more considerate and thoughtful on approaches in patient care that permits more for those in our care (Cody, 2006).

The research question proposed for this study is to investigate the basic social process that individuals undergo to live with the diagnosis of cirrhosis. Knowledge attained from this research will contribute to the intellectual foundation on a transition point in this chronic illness.

This work will additionally be a factor in linking the exclusive individual response to a diagnosis of cirrhosis with that which is contended to be representative phases of the illness journey (Morse, 1997; Thorne & Patterson, 2000).

CHAPTER 3

METHODOLOGY

In this chapter the specific aspects of methodology, research design, setting and sample size, recruitment of participants, data collection, data management, data analysis ethical considerations, and study rigor are delineated and described.

The purpose of this study was to discover a theoretical explanation about the basic social process that one undergoes after being diagnosed with cirrhosis and living their life with a threatening chronic disease and illness. Grounded theory was utilized as the type of qualitative method. This method is particularly useful in uncovering information and a different understanding in an area where there is little known and phenomena of inquiry are characterized by contextual factors that preclude exact definitions (Glaser, 1978; Glaser & Strauss, 1967). Grounded theory provides a rigorous way to develop an understanding of the experience of illness from the patient's perspective. A comparative analysis of data enables the generation of conceptual categories. These conceptual categories elucidate the theoretical relationship of the process. These categories are further integrated to generate a substantive theoretical relationship of the process (Coates, 2008; Conrad, 1990; Glaser, 1978; Glaser & Strauss, 1967). There are four philosophical underpinnings of grounded theory methodology. These foundational elements are that the research is directed at a human reality, there is commitment to the participant's viewpoint, context is valued, and theory is discovered inductively (Glaser, 2001; Glaser & Strauss, 1967; Speziale & Carpenter, 2007). The discovery of knowledge from

this research approach serves to enhance the comprehension of issues that have not yet been characterized, by investigating the reality of others, fine tuning perceptions of that actuality, and operationalizing those concepts (Glaser, 1978). When a human experience, which has not been distinguished in a discipline, is examined and evaluated with a grounded theory approach, the basic social processes of a particular phenomenon are differentiated, which allows for an improved understanding of that encounter. As data are accumulated and characteristics become constant, concepts are developed, the relationship between concepts is discovered and theory is generated (Corbin & Strauss, 1991; Glaser & Strauss, 1967). This systematic examination of phenomenon and intellectual management of subject matter permits an augmentation in clinical knowledge with an emphasis on understanding a significant patient situation.

Grounded theory methodology was utilized in this study and served to generate knowledge and understanding about the basic social process that an individual undergoes and the patterns of behaviors that are experienced as one lives life with a diagnosis that has the potential to end in premature death. The aim of this research study was to discover a theoretical explanation about this phenomenon (Glaser & Strauss, 1967). This research methodology provided insight into the course that one undergoes and the patterns of behaviors that one experiences from the time of the diagnosis of cirrhosis to the basic social process that one undergoes to live with this diagnosis. The results of this research was constructive on two fronts. Foremost, this is an area in a serious health-illness care transition where there had not been clinical study or investigation. Secondly, with knowledge in this patient care realm augmented, more complete provider responses can be implemented (Cody, 2006; Corbin & Strauss, 1991).

Research Design

This nursing study utilized a naturalistic design. There are five principle assumptions of a naturalistic approach for inquiry. These include that there are multiple constructed realities which can only be studied holistically, the researcher and the subject of inquiry interact and influence one another, hypotheses are both time and context bound, there is idiographic interpretation where conclusions are drawn from the particulars in the study, and the inquiry is value bound (Lincoln & Guba, 1985). This study, specifically utilized a classical grounded theory model (Glaser, 2001). Grounded theory was used to explain the basic social process of how individuals live with the diagnosis of cirrhosis. The final product of this research provides this explanation and the ability to predict individual behavior (Glaser, 2001; Glaser & Strauss, 1967).

Setting

This study was conducted at a tertiary care, teaching facility in the Chicago Metropolitan area. The institution offers an advanced hepatology fellowship program and is a liver transplant center. It is a 450-bed facility, with an outpatient hepatology population of approximately 6000 patients. Of those patients, there are over 1200 patients who have the diagnosis of cirrhosis. In 2014, 29 individuals underwent liver transplant at this facility for end stage liver disease (M.Mitchell, personal communication, August 17, 2015).

Sample and Sample Size

A purposeful sample of individuals who are diagnosed with liver disease that has advanced to cirrhosis were recruited for this study. Individuals were chosen who could describe their response of what it is like to live day to day with cirrhosis and the processes that they

underwent to live their lives with this life threatening diagnosis. It was expected that approximately 20 study participants would be needed to reach data saturation, when there was no new information or findings being generated (Glaser & Strauss, 1967; Speziale & Carpenter, 2007). This number of study participants was estimated from the literature review for this study with qualitative grounded theory studies having average sample sizes of 18 participants.

The inclusion criteria for this study was that individuals be over the age of 18 with a diagnosis of cirrhosis. Study participants needed to speak English. The individuals recruited for this study had a Measurement of End Stage Liver Disease (MELD) score of < 20. The MELD score is a severity index for patients with end stage liver disease. A score of < 20 usually represents a population that although very ill, would continue to have the physical and cognitive ability to participate in an interview (Merion & Dykstra, 2004). Exclusion criteria included anyone who continued to struggle with illicit drug and alcohol dependence, those who had developed encephalopathy, and those who were in the pre-transplant evaluation, or listed for transplant.

Recruitment

Recruitment of this sample population initially began with a meeting with the Department Chair at the facility where this study was conducted. The purpose of this meeting was to explain why the study was being conducted, which was to discover a theoretical explanation about the process that patients undergo when coming to terms with a specific diagnosis with an uncertain future. After this meeting, a separate meeting time was set with each of the hepatologists, whose support was being sought for this study. The study purpose was reviewed and it was decided that patients would be invited to participate in the study at the clinic appointment with their

hepatologist and then referred directly to this investigator. Each of these physicians wrote a letter of support for this study (Appendix A). A recruitment flyer was approved by IRB for additional study participation, but was not needed or utilized (Appendix B). For those individuals who expressed interest in study participation, their name and medical record number was given to the investigator for recruitment contact. At that time, the purpose of the study was discussed, initial study participation was determined, and a mutually agreeable time was set for a phone interview.

The hospital where this study was conducted is the place of employment for this researcher. In order to be non-biased during patient recruitment, the process of enrolling study participants was customized to avoid preconception and bias for both this student and study participants. This institution has four practicing hepatologists. This student supports two of those physicians in their outpatient practice. To maintain objectivity and avoid preconception, patients were recruited from the two practicing hepatologists that this student does not have a clinical relationship with.

Data Collection

Data were collected during a one on one phone interview with study participants. Phone interviews were conducted at a date and time designated by the participant. Participants were initially informed that the interview would take about an hour in duration. Each interview was audio-recorded and all participants were informed of this procedure. The primary investigator conducted the interviews. In the interviews, patients were asked to describe their response to being given the diagnosis of cirrhosis and to tell their story from initial diagnosis to the present time.

The interview was structured to elicit clarity, depth, and fullness. The method of interviewing was constructed to be characteristic of both a tree and branch and a river and channel technique (Rubin & Rubin, 2005). This approach allowed for main questions related to the research topic to be addressed while maintaining flexibility for exploration of captivating themes that emerge. An interview guide was used in order to structure the interviews and keep the investigator and participant focused on the topic of the diagnosis of cirrhosis and the impact of this occurrence. The questions outlined on this interview guide were both ordered and broad main questions. These questions served to examine the topic being investigated and to open conversation with the study participant. Follow-up questions were used during the interview to delve further into particular themes or potential categories and pursue those topics. Probing questions were used to elicit more depth and to describe details (Rubin & Rubin, 2005). Data collection continued until data saturation was achieved. Data saturation refers to the repetition of discovered information and confirmation of previously collected data. It is the point where there no longer any new information, categories, or codes being generated. Data collection was complete at this point (Glaser & Strauss, 1967; Speziale & Carpenter, 2007). This interview guide was approved by the IRB of the facility where this study was conducted (Appendix C).

Demographic information was obtained directly from the participant during the study interview. This information included age, sex, marital status, occupation, and educational level. These characteristics added supplemental information on the study sample participants.

Data Management

Participants were assigned a study number. Transcripts only contained this number in order to ensure patient confidentiality. Interviews were tape-recorded and each interview was

labeled with the participant's assigned study number. After the completion of the interview, the audio tape was transcribed verbatim by this investigator. The taped interviews were stored in a locked file cabinet at the investigator's private residence. Consent forms were also stored at the researcher's private residence in a separate locked drawer. This researcher replaced any identifying information on the recordings with a pseudonym. Identifying information that had no relevance to context was deleted. The chair of this student's dissertation committee had access to all interviews and transcriptions.

Data Analysis

The data analysis technique used in grounded theory research is constant comparison (Glaser & Strauss, 1967; Speziale & Carpenter, 2007). This method enables the establishment of categories based on the similarity of content. There are four processes that comprise the constant comparative method and are identified as open coding, axial coding, the emergence of a core category, and delimiting the theory. The initial process of constant comparison begins with open coding where the investigator breaks down information into data bits. The purpose of open coding is to generate categories that have similar properties. To ensure the accuracy of participant descriptions and analysis, initial coding of data was done under the supervision of Dr. Lee Schmidt, the committee chair for this research. The data source was preserved by having the participant number and page number of the transcript placed in the margin of the working category (Glaser, 2001; Glaser & Strauss, 1967).

A fundamental rule with constant comparison is to always re-examine newly coded data with previous incidents that were coded into either the same or different category (Glaser & Strauss, 1967). The rationale for this process is to clarify properties within each category and to

begin to integrate the occurrences and components into a unified whole. Memo writing was used throughout this research phase in order to preserve theoretical ideas, sort concepts, record impressions, provide an immediate example of a thought, and to aid this investigator's memory in order to avoid bias, contribute to data capacity, and the vision of an emerging concept (Fetterman, 2001; Glaser, 1978; Glaser & Strauss, 1967; Kreuger & Casey, 2009; Speziale & Carpenter, 2007).

The second process of data analysis is to compare incidences and properties of the existing categories that emerged from the initial analysis and coding. This is labeled axial coding. It is where the investigator begins to identify relationships and develops broader conceptual categories from the essential properties and characteristics that differentiated the initial groupings in open coding. The researcher continued to compare each broad conceptual category with the initial codes that were generated in open coding in order to assure that categories were mutually exclusive. The development of these conceptual categories allowed the investigator to develop insight into the relationship between the data and theory. Conceptual codes provided direction to the framework that was being developed and moved the work from descriptive to theoretical.

The third process of constant comparison is the emergence of a core category, which accounts for most of the patterns discovered and helps to integrate the categories into a unified whole. This core category has a central relation to every other category, describes all dimensions of the phenomenon, and it is a steady and constant recurrence in the data. The development of this core category is the step of conceptual integration and represents the fundamental elements within the theoretical structure (Glaser, 1978; Glaser, 2001; Glaser & Strauss, 1967; Speziale &

Carpenter, 2007). It is with theoretical sensitivity for the generated codes, the processing of sampling, memoing, and data saturation that the researcher is able to complete the fourth and final process of constant comparison (Glaser, 1978).

The fourth process of constant comparison is to define the emerging theory. There are three major steps in defining the emerging theory. They include data reduction, sampling of the literature, and selective sampling of the data. Reduction of data is the reduction of categories that have equivalence into a cluster, which form a category of a broader scope when combined. Selective sampling of the literature serves to expand the current work and relate it to other theories. As key concepts become evident, the researcher can investigate under which conditions these concepts occur, and if these occurrences are fundamental to the emerging theory. At this time, the researcher may engage theoretical sampling and collect additional selective data to develop hypotheses and augment the properties of the main categories. Memoing is again utilized at this stage of research to aid the investigator in preserving theoretical notions, generalization and impressions. Writing the theory is the final step in the constant comparative method. This is the step where the researcher is confident that the data, memos, and the theory that has been developed accurately reflect the phenomena studied. The researcher is thus assured that the analysis of data and subsequent systematic ordering is both convincing and credible (Glaser, 2001; Glaser & Strauss, 1967; Speziale & Carpenter, 2007).

Ethical Considerations

Investigators must always consider the ethical implications when conducting any research study. These areas include informed consent and maintaining confidentiality while handling sensitive information. In grounded theory, the researcher and participant have a private and

personal relationship, which means that one needs to be prepared for unexpected occurrences.

Study participant interviews may uncover painful, difficult, and sensitive issues, which have not been easy for the individual. In each of these incidences, the researcher needs to be aware that these issues can arise and to always ensure that the patient's welfare comes first, with follow-up care and planning for recommendations in advance (Speziale & Carpenter, 2007).

This study had Institutional Review Board approval at both the Institutional Review Board of the home institution of this student and the Institutional Review Board of the participating site (Appendix D). Study participants underwent a verbal informed consent process (Appendix E). The purpose of the study was outlined and the duration of participation was addressed, which was expected to be a one-hour time commitment. The risks to this study population were determined to be minimal, likely consisting of only fatigue related to the interview time requirement or sadness and discomfort in retelling their experiences with the diagnosis of cirrhosis. Letter and numeric identifiers were used as codes to aid the researcher in organizing data and to protect participant identification. Consent for participation was obtained verbally from participants before the interview was conducted. A copy of this consent was mailed to study participants (Appendix E). Audio recordings of interviews and transcriptions will be destroyed within a year of study completion.

There was no expected benefit to the participants in this study, except that they are contributing to knowledge that could affect future care of patients who are diagnosed with cirrhosis. Participant involvement in this study was voluntary. Those participating in this study were informed that they did not need to answer any questions that they did not want to and that they could withdraw their consent to participate at any time, without consequence. Each

participant was informed at the beginning of the interview that all information would be kept confidential. Participants in this study were reimbursed with a \$25.00 Visa® gift card for remuneration for their time.

Study Rigor

This investigator adhered to rigor in this study by upholding the general principles of qualitative research and meeting the expectations of those principles specific to the generation of a grounded theory. The philosophy of rigor pertaining to qualitative research includes the universal principles credibility, dependability, confirmability, and transferability (Glaser & Strauss, 1967; Lincoln & Guba, 1985). Credibility was maintained throughout this work by this investigator being engaged with the subject matter of transition points in chronic illness and the diagnosis of cirrhosis. This investigator was committed to scope and depth throughout the inquiry process and was open to the multiple influences and contextual factors that participants described. The investigator reported participant information faithfully and with precision, and achieved data saturation with emergent categories before participant closure. Study findings were reported diligently and with transparency. Explicit participant statements were reported that support this investigator's analysis, judgment, and conclusions.

With credibility of this study being demonstrated, dependability was then substantiated. Additionally, the process of inquiry verifies dependability. This researcher conformed to the methodological principles of qualitative research by maintaining a commitment to context flexibility, significance, and remained open to new information. The constant comparative method of data analysis was employed with inductive reasoning, which allowed for the advancement from concrete descriptions to a theoretical level of science. Memoing was utilized

throughout this study to record any preconceived thoughts, biases, or ideas that may influence interpretations or later findings (Lincoln & Guba, 1985; Speziale & Carpenter, 2007).

Confirmability was established in this study by the preservation of an audit trail of raw data, theoretical notes, and the accounting of the process of data reduction and reconstruction. The appraisal of data coding and synthesis that led to the integration of concepts and theoretical conclusions was reported. This allows for the judgment of analytical accuracy, internal coherency, and future appraisal (Burns & Grove, 2009; Glaser & Strauss, 1967; Sandelowski & Barroso, 2002).

Transferability was determined with this work being applicable for others. The results of this study were reported with sensitivity toward reader recognition of the phenomenon and identification with theoretical connections. The investigator presented the analysis of data with descriptions that are solid and substantial in order to provide the widest range of information for others. The relevance of data from this study was integrated with existing nursing literature for both professional knowledge development and applicability to current nursing practice situations. The end product of this research allows for a clinical perspective that assists in the prediction and explanation of patient experiences, provides a standpoint to direct the clinician's influence, and demonstrates where future research endeavors are warranted (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Speziale & Carpenter, 2007).

Specific principles of rigor that are applicable to the generation of grounded theory include that the theoretical framework is significant and provides the practitioner with an explanation and prediction of behavior (Glaser & Stauss, 1967). This enhanced clinical perspective permits an improved understanding and allows for further influence with the

situation. Lastly, the theory generated from grounded theory methodology should provide a theoretical guide for future research (Glaser, 1978; Glaser & Strauss, 1967).

The theory generated from the data in this study meets these requirements and is relevant to nursing practice by providing a framework to predict and explain the basic social process that one undergoes after being diagnosed with cirrhosis and living their life with a threatening chronic disease and illness. This theory has clear conceptual categories with hypotheses that can be operationalized and further tested in quantitative research. The theoretical structure that was developed from the conceptual categories has a natural and inherent fit and is reported in language that is easily understood, making applicability in practice straightforward (Glaser & Strauss, 1967).

CHAPTER 4

RESULTS

In this chapter, the study findings of the basic social process of living with the diagnosis of cirrhosis are presented. The chapter begins with a discussion of the study sample, recruitment, data collection, and analysis utilizing the grounded theory methodology. This section is followed by the presentation of findings and a discussion of the methodological rigor of grounded theory research that was upheld in this study. A summation then concludes this chapter.

Sample

Seventeen study participants were interviewed for this study. All individuals were active patients within the Hepatology practice at the institution where this study was conducted. Of those participating, eight participants were male and nine participants were female. The ages of participants ranged from 50 years old to 76 years old, with a mean age of 62.7 years old. The time since the diagnosis of cirrhosis ranged from two months to three years. Study participants reported educational backgrounds of completing 9th grade to holding a terminal degree of PhD. Participants described personal significant relationships of 7 (41%) being married, 4 (23%) being single, 2 (12%) were widowed, 1 participant (.05%) had a lifetime partner, and 3 (18%) were divorced. The cause of cirrhosis, for the majority of participants, was Hepatitis C, with 13 individuals (76%), holding that diagnosis. Of those individuals, 5 participants (38%), contracted Hepatitis C from receiving either blood or blood products, before there was testing capability available. Two individuals (12%), developed cirrhosis because of alcohol dependence, 1 study

participant, (0.05%), had an autoimmune disorder, and 1 (0.05%), participant had an unknown cause of cirrhosis. A chart of the sample characteristics is included in Appendix F.

Recruitment

Sample recruitment began by the researcher having an initial meeting time with the two referring physicians from the Hepatology practice at the institution where this study was conducted. During this meeting, the study objective and methodology were reviewed, along with inclusion and exclusion criteria for potential study participants. Physicians agreed to discuss the study with those eligible patients within their practice at an outpatient visit. For those individuals who agreed to participate in this study, this researcher was provided with their names and medical record number, so that a phone call could be made to arrange for an interview date and time.

Eighteen individual names and medical record numbers were given to the researcher over a four-month period. Individuals were initially contacted by a phone call, and after a personal introduction, they were asked if they would like to participate in the study. Of the eighteen individuals contacted, seventeen agreed to participate in the study. At this point, a date and time that was convenient for the participant to be interviewed was established.

The interview began with the researcher reading the informed consent to the participant. At the end of reading the consent, it was reviewed that the individual could refuse to answer any questions that they did not want to, along with being able to terminate the interview at any time. The individual was then asked if they verbally agreed to participate in this study. Participants were mailed a copy of the consent along with a \$25.00 VISA® gift card as compensation for their time.

Data Collection and Analysis

Interviews were done as a phone interview, which was conducted exclusively by the researcher. Each interview was audio recorded and ranged from 20 to 75 minutes. After verbal consent was obtained, the interview began with broad general questions that included age, sex, marital status, number of children, years of education, and occupation. This approach allowed for a level of comfort to develop between the participant and researcher, along with gaining supplemental information regarding the study participants.

Following these introductory questions, the researcher relied on an interview guide to maintain the focus of both the participant and researcher on the topic of the diagnosis of cirrhosis and the aftermath of that occurrence. These questions were designed as both ordered and open ended questions, in order to have the main questions of the research study answered, along with simultaneously allowing for flexibility to explore relevant data that might emerge during the study interviews. Interviews were conducted in an informal and relaxed style utilizing the tree and branch and river and channel approaches (Rubin & Rubin, 2005). The researcher asked follow up questions when there was need for further information or clarification, along with probing questions to elicit depth, or enhance details. At the end of all interviews, participants were asked if there was any further information that they would like to share that may not have been asked. Of the seventeen participants, six individuals voluntarily gave permission to be called again if more information was needed. These participants were not re-contacted.

Participants discussed their experience of being diagnosed with cirrhosis and the consequence of this occurrence in a straightforward and spontaneous manner. Individuals described their experience from initial diagnosis to an end result of being able to live with this

diagnosis. During each interview, the researcher took notes to facilitate follow up questions and to assist in remembering significant interview points for subsequent memo writing. After five interviews, a process pattern was becoming evident. During the next five interviews, the process structure strengthened, key categories emerged, and relationships between these categories began to solidify. At this point in data collection, the researcher met with the Principal Investigator and Committee Chair of this study for guidance and to confirm direction. In the following interviews, theoretical sampling was applied with additional focused questions asked to augment category properties and to expound on developing hypotheses (Glaser, 1978; Glaser, 2001; Glaser & Strauss, 1967). Data collection continued until category saturation occurred, which is when there was repetition of discovered information, confirmation of previously collected data, and there was no longer any new information, categories or codes being generated (Glaser & Strauss, 1967; Speziale & Carpenter, 2007).

Before data collection commenced, the researcher compiled a list of expected responses as a self-monitoring tool. This task was performed in order to limit personal bias and maintain theoretical sensitivity. In identifying potential bias before the interviews began, the investigator was more capable in preserving sensitivity to subtle and varied responses while being able to abandon ideas not supported by the data obtained from participants (Chiovitti & Piran, 2003). There were no unexpected or untoward events during the data collection phase of this study.

Data analysis was completed using the constant comparison method, where data collection and analysis occur simultaneously (Glaser, 1978; Glaser & Straus, 1967; Speziale & Carpenter, 2007). In the initial phase of data analysis, the researcher completed open, first level coding. This was done by reviewing interview transcripts line by line and circling any key

phrases, words or sentences, which were identified as data bits. These units of analysis were then grouped by similar key words or phrases. As interviews were completed and transcripts were coded, these codes were compared with previous codes and either associated with the existing codes, or new codes were generated. This process clarified category properties and begins the integration of components into a unified whole.

Memo writing was utilized throughout the coding process. This technique assisted the researcher to preserve theoretical ideas, sort concepts, record impressions, aid the investigator's memory, and contribute to insight for the emerging concepts (Glaser, 1978; Glaser & Strauss, 1967). These theoretical memos contained notes on data sorting, associations between codes, ideas on data grouping and the skeletal structure of the emerging conceptual categories. As conceptual relationships developed, theoretical sampling was utilized by the researcher to investigate specific participant responses. These additional searching questions were used to stimulate participant responses on particular areas of the emerging conceptual structure and to examine categories that had diminutive data bits. If these codes did not produce or support a developing category, this information was placed in a miscellaneous category and reviewed again during data collection to ensure that potential codes were not overlooked.

At the end of first level coding the researcher had compiled 203 exclusive codes. Second level, axial coding involved merging these unique codes into broader conceptual categories. The researcher continued to compare the more extensive conceptual categories with the initially generated codes to assure consistency. Memos were again utilized as a reference for the investigator's recollection, and to preserve the flow of theoretical notions, generalizations, and impressions. Transcripts were re-examined to confirm that there was a strong fit between the data

and the emerging model. A core category was identified by studying each of the properties of the conceptual categories and the review of theoretical memos. This core category had a central relation to all conceptual categories and it represented the fundamental elements within the theoretical structure (Glaser, 1978).

At the conclusion of axial coding, in addition to a core category emerging, there were twelve conceptual categories identified. Conceptual definitions and properties of each of the categories were identified. The conceptual categories were ordered in a linear progression with an identified process that had a beginning, middle and end point. The end point of the process was the individual living with diagnosis of cirrhosis.

The next section of this chapter presents the theoretical process, the core category and the conceptual categories that were generated from the data. This section is concluded with a schematic of the process.

Findings

The following findings answer the research question of what is the basic social process that a patient undergoes after being diagnosed with cirrhosis and living with a life threatening, chronic disease and illness. This section begins with the basic social process that emerged from the data and the core category that was identified. It is followed by the conceptual categories and the properties associated with those categories. Categories are illustrated by quotes from study participants.

In the presentation of findings, the core category is underlined, bolded and italicized (***core category***), the conceptual categories are bolded and italicized (***conceptual categories***), and the properties of the category (*properties of the category*), are italicized for the ease of reader

identification. Participant quotes are provided to support the category descriptions. Each quote is followed by a bracket, participant identifier, and page number of the transcript. The first 10 participants are categorized as Group A and the remaining 7 participants are in category B, due to the grouping on the recording device. For example, [A.1.1] represents participant number one in group 1, page one of the transcript, [B.13.5] represents participant 13 in group 2, page 5 of the transcript.

Basic Social Process

Based on the data, the process of living with the diagnosis of cirrhosis is a linear process that begins with *having a damned day*, when individuals are told of the diagnosis. This is followed by a period where individuals are *preparing themselves for the worst*. These two categories combine to place the individual in a state where they *do nothing*. This component of the process sets the condition for the individual to *move forward*, when they can *work through it* and *accept it* to where they are able to *not worry about it*. *Being in good hands* supports the individual *to do everything that they can for themselves*, putting them *in a good place*, where they *have the other side of the coin* and are *able to live day by day*. This process is illustrated in Appendix G.

Core Category: *It is always the monkey on my back*

The core category has a central relation to all categories with a steady recurrence in the data. It has explanatory capacity and this identification assimilates conceptual categories into a unified whole (Glaser, 1978). *It is always the monkey on my back* emerged as the core category from the data as the basic social process that depicts what living with the diagnosis of cirrhosis entails. This core category was a pervasive and persistent event across all twelve conceptual

categories. Participants in this study moved through a linear process of coping and acceptance to reach an end point of stability. Throughout each phase of this process there was the fear and concern for anticipated negative health events. *It is always the monkey on my back* illustrates the personal burden that individuals endure when they are experiencing a disease and illness course that has a negative and unpredictable trajectory. These individuals carried the weight of this strain and stress privately. The properties of this core category are *ever present* and *persistent worry*. All participants spoke of this diagnosis as being perpetually on their mind. An individual response that particularly illustrates the property of *ever present* is personified in the statement of, “It is like the ghost that is always over me, I don’t know when it’s going to jump at me. You know it is always there” [A.6.4]. This participant went on to speak of an earlier time of counseling sessions and learning the skills to deal with difficult life situations. She recalled those teachings for application in this life position and the difficulty one has in having an unresolvable issue. The constancy of living with the diagnosis of cirrhosis was noted by a participant who stated, “It is always present. It is always at the back of my mind. I’m hoping I’ll make it with the Harvoni, [Hepatitis C treatment], but I know that there are no guarantees. Having liver disease, it’s like sitting on a time bomb” [B.12.3]. This participant was keenly aware of how the diagnosis of cirrhosis affects longevity. She went on to say, “It’s all hard. I try to be positive and not let it get me down. My mother lived to her 90’s. I’m not going to number my days, but I’d like to make 80. That would be great, but there is this monkey always on my back” [B.12.4]. Another participant spoke frankly about his concerns for longevity. After being diagnosed with cirrhosis, stating, “I asked Dr. R. I said this is very serious, what are my chances of living with this for long. He said, if we don’t find the cure your Hepatitis C, you probably won’t make it to

age 70. [this participant was 68 years old]. So, I have this thing hanging over my head” [A.7.5]. Other participants spoke of the continual personal encumbrance with having a diagnosis that is permanent. One participant stated, “I think about it every day. I have a disease that is not curable. It is constantly on your mind” [B.17.4]. Another participant discussed living with the diagnosis of cirrhosis after successfully eradicating Hepatitis C. He stated, “that it isn’t hard living with the diagnosis, but it is always hanging over your head. You might develop liver failure or something” [B.13.4].

Participants described their struggle with the diagnosis of cirrhosis and the *persistent worry* that comes with a diagnosis that comes with one guarantee; that things are going to get worse. Living with the *persistent worry* of getting liver cancer was articulated by many participants. In the words of one participant, “It (liver cancer) is constantly on your mind, when you know that you have gone to the progression of cirrhosis. That’s the typical case of progression. That (liver cancer) is what happens” [A.10.4]. Other participants spoke of the constant concern for a decline in liver function with the words, “I wonder sometimes, is this my liver getting worse, or am I just getting older” [A.4.7]. A similar participant response in regards to this persistent worry is in the statement, “Every time I have some trouble with something, I think, is this my liver failing me” [A.7.9]. These participants were referring to subtle declines in their physical stamina. Another participant had comparable worries and expressed these anxieties in the statement, “You think about getting ill, you know you could die, you might develop liver failure” [B.13.2].

There are twelve conceptual categories that represent the process that one undergoes to live with the diagnosis of cirrhosis. Each of these categories and their properties are discussed in

the following sections.

Having a damned day

The basic social process of living with the diagnosis of cirrhosis begins with individuals hearing that they have the diagnosis of cirrhosis. The first category of the theory is *having a damned day*. This is the day that individuals hear the news that they have a long term chronic condition, that for most will be a terminal event. All participants, without exception, described knowing how unfavorable this diagnosis was for them. Additionally, there was an instantaneous emotional reaction with realizing that one holds a diagnosis that is not curable. The properties of this conceptual category are *knowing it was bad* and *being shocked*. The initial property of *knowing it was bad* is articulated with participants detailing the abrupt awareness of having a permanent and non-repairable condition. One participant verbalized this property of *knowing it was bad* with the statement, “Here I am with this life-threatening diagnosis “[B.14.8]. Another participant, who was 52 years old, articulated this comprehension in stating, “I thought, I am going to have this for the rest of my life” [A.2.3]. Individuals were aware of the vital function of the liver. A participant expressed this perception with the words, “You know how important your liver is, you can’t live without it” [A.5.5]. Another participant echoed similar words with the response of, “when your liver goes, it is over” [B.12.4] .

Participants described an early expressive and emotive response when hearing that they have the diagnosis of cirrhosis and *knowing that it was bad*. There were the personal accountings of one participant, who after undergoing a liver biopsy was told that she had cirrhosis. Her words were, “I hear that I have cirrhosis. It made me feel so bad. I started crying It was awful. I thought, I am a dead person” [B.11.2]. Another participant had a similar response, after being

diagnosed, with the response, “My heart fell to my stomach” [A.1.4]. Others spoke of similar personal reactions to the distress that accompanied this diagnosis and *knowing it was bad*. One participant spoke about the day he was diagnosed with cirrhosis with the remembrance, “I was pretty upset, the first thing I thought was how many years do I have left. Then I thought this is my payback for mistakes that I made when I was young” [B.16.2]. Another participant stated when diagnosed that, “All I thought was, how much longer do I have to live, it was scary....very scary” [A.1.3]. A parallel sentiment that a participant expressed after being diagnosed was with the words, “It was scary. I knew I would be going through life with my liver failing me” [A.3.4]. Another participant, who had been diagnosed after imaging, recalled, “Here I am with cirrhosis and I’m scared, then I go on the internet and I look up all this stuff and I thought, I am in for a long ride” [A.8.4].

The second conceptual property of this category is *being shocked*. The preliminary emotional effect of this diagnosis was intense. Participants described the experience of hearing that they have cirrhosis as disarming with an immediate reactive recoil. The following participant responses reflect this direct and instant emotional response of *being shocked* with the statements of, “I couldn’t place it at first [A.10.5] and “I was dumbfounded” [B.17.4]. One participant told of their initial response of being told that they had cirrhosis with the remembrance, “She said, ‘unfortunately you have cirrhosis’, I said WHAT?” [B.16.2]. Others spoke of not being able to comprehend the information at first, with the personal accountings such as, “I didn’t know what was happening” [B.13.4] and “I didn’t understand what was going on” [A.6.3]. Another participant spoke directly with the aftermath of being diagnosed with cirrhosis and stated, “It took a while to bounce back from that one” [B.15.3].

This initial category of the process is followed by a somber period of fear and trepidation. It is a time where the individual becomes consumed with death. They prime themselves for the end result of having a diagnosis that bears little mercy to those that hold it. The next category of this framework is where one is *preparing myself for the worst*.

Preparing myself for the worst

The second category, *preparing myself for the worst*, is a period of personal despair and despondency. The properties of this category are *preparing for death*, and *the fear of getting liver cancer*. Participants spoke at length about knowing that they had been given a life limiting diagnosis. Each participant, in their own way, talked about knowing that death is the final outcome of having cirrhosis. Many individuals spoke of wondering how much longer they would have in this life. Others spoke of a passing future and beginning to number their days. Some worried that there was so much damage to their liver that they were already close to death. Specific participant responses that demonstrated this personal weight with the property of *preparing for death* were, “I was living like I was dying” [A.6.3] with another participant stating, “I felt like I was the walking dead” [A.1.7]. Participants spoke of knowing the insidious and elusive nature of cirrhosis. One participant recalled, “So here’s this big word (cirrhosis) that I have. You can’t see it, you can’t touch it. The liver is silent you know” [B.14.6]. This participant was discussing the time after being admitted to ICU for an acute variceal bleed and having no prior symptoms of her liver disease. The context of her statement was in how difficult it is to have an overall asymptomatic disease until one has a life-threatening event.

Participants talked about knowing what the cause of their death would be. One participant, who was a 65 year old male, and had been diagnosed with cirrhosis for a little over

two years, reflects this mindfulness saying, “I know what’s going to take me out” [B.16.4].

Another participant had a similar forthright outlook about his mortality with the words, “Of course, I’m still going to die from this” [A.7.5]. This individual had shared that he had recently gone through treatment for Hepatitis C, and although cured from that disease, was aware that he still held the diagnosis of cirrhosis, and that this diagnosis is not curable. He remembered and repeated his doctor’s words, “Dr. R. told me, the damage is already done. All he did was to slow down the aggressive progression. Once there is cirrhosis, the liver can’t regenerate” [A.7.5]. The participant knowledge that the diagnosis of cirrhosis is permanent and not resolvable is again portrayed with the reflective words of: “I was on treatment (for Hepatitis C) and I thought that I could reverse it (cirrhosis). But I have cirrhosis and the liver can’t be cured” [A.5.7].

The property of *preparing for death* and the apprehension that one has regarding the closing outcome of end stage liver disease is acutely embodied in the participant statement of, “I have seen people die from liver disease, it is a slow evil process” [B.15.3]. This individual was referring to his brother, who had succumbed to end stage liver disease secondary to alcohol abuse. He was using this experience as a reference point for himself. Another participant’s retort of, “The hardest part of having liver disease is that you know how it is going to end” [B.13.7], again demonstrates this anticipation for an unfavorable end. This individual was 50 years old and had been given the diagnosis of cirrhosis a little over a year ago.

Individuals contended with the *fear of getting liver cancer*. Most participants were intensely aware that the progression of cirrhosis, for many, will be liver cancer. One participant, who was later in years at age 73, stated, “It’s the cancer that I can’t live with, I can live with the Hepatitis C” [B.12.7]. Another individual, who was 61 years old, spoke in a matter of fact tone

and stated: “When you have cirrhosis, there is the threat of liver cancer. Knowing the cancer can come, it’s the cancer I worry about. The cirrhosis can turn to cancer” [B.17.8]. The relentless worry of *getting liver cancer* is illustrated in the explicit words of one participant who stated, “I worried about the liver cancer, I worried. I worried. I worried so much. I worried so much and it (liver cancer) popped up” [A.10.5]. Another participant echoed this sentiment with similar words and stated, “Knowing that the cancer can come, the cancer threat, all because of the darn cirrhosis. That really bothers me, knowing that I can get the cancer” [B.11.4]. This participant was 58 years old.

The first two components of this process, that of *having a damned day* and *preparing myself for the worst* combine and place the individual in a stationary state of *doing nothing*. This is a time where the individual distances themselves from others and is physically inactive.

Doing nothing

In the *doing nothing* phase of this basic social process, the individual is in a motionless position. It is a period of inactivity and a private time where one separates themselves from others. The properties of this category are a *corporal immobility* and *isolation*. Participants spoke of being in a physical stationary state. This was a time that they were unable to engage with others. The first property of this category, is *corporal immobility*. It is a time where one is physically dormant. There is a pause, which one participant expressed in the words, “I needed to be still. Being still, so that is what it takes, so be it” [A.2.3]. Another participant recalled this period of inactivity with the words, “I needed to be calm. I needed to stay calm. I felt bad for a long time. I don’t know if I was not feeling good or knowing what is ahead” [A.4.7]. A similar response from a participant, who described his time after diagnosis was explicit, stating, “I was

numb, I was trying to remain normal” [B.11.5]. This time of physical inaction was not time bound. One participant recalled this phase of the process stating, “I did nothing for a couple of months” [B.14.3]. Another participant spoke about his time after the diagnosis of cirrhosis, and being physically inactive for an extended period of time. He relayed, “it was so hard on me, it was hard. The first year was really hard. I didn’t feel good. I didn’t want to do anything” [A.9.6]. Other participants expressed similar statements of physically not feeling well, and that these symptoms hindered activity. One participant cited, “the first couple of years was very hard. I felt ill. I just felt bad. I was out (of work) for most of the time. I finally had to go on disability” [A.7.6]. Another participant stated, “I was so weak, I couldn’t go outside. For a while, I couldn’t go outside” [A.1.4].

The second property of this category is *isolation*. This is a time of solitude, where individuals were unable to participate in routine life events. They were disengaged. One participant articulated this state, “I was in my own little world” [B.12.4]. Another portrayed this period of sequestration stating, “I didn’t want to be around nobody, I kept away from my grandchildren. I just didn’t want to be around nobody” [A.1.5]. This was a time where the individual had unplugged themselves from everyday activities. There was a loss of interest for those events that they had previously looked forward to. It was a joyless time. These sentiments were aptly characterized with one participant who spoke of not participating in scheduled events, stating, “I stopped doing things that I had planned” [A.8.6]. This participant was referring to an arranged vacation and family occasions.

This component of the process sets the condition for the individual to *move forward*, where there is an inner core pivot that allows the individual to regain motion. As one is able to

move forward, they can then *work through it* and *accept it*, to where they are able to *not worry about it*. These three categories follow *moving forward*.

Moving forward

In the *moving forward* phase of this basic social process, participants emphasized the essential personal energy and inner drive that was needed at this point of the process. It was this personal impetus that pulled the individual out of a low-spirited time. The properties of this category are *wanting something else* and *needing to move on*. The first property of this category is *wanting something else*. One participant stated, “I wanted more” [A.3.8]. In this phase of the process, there had been an emotional reset. Participants acknowledged that this detached and isolated place was unfavorable for them. One participant stated, “I couldn’t stay in that place” [B.13.6] reflecting the recognition of the need to separate from this dismal time. Another participant spoke of this desire for *wanting something else* with the words, “I looked into the mirror and I didn’t like what I saw” [A.2.7]. Participants specified that they needed something different and did not want to remain in a fixed position. This static place of *doing nothing*, was less tolerable than the diagnosis that they were given. This sentiment is captured in a participant accounting, “I knew that I needed to do something” [B.2.5]. Another participant spoke of *wanting something else* for her family. This individual was a 60 years old woman, who was an active participant in the care of her grandchildren. She stated, “I wanted more, I want more for my grandchildren. I want to live” [A.3. 5]. Individuals spoke of leaving this void and that the parting from this time was up to them. This is a time in the process, where there is a thoughtful recognition that their personal desire for *wanting something else* was up to them.

The second property of *needing to move on* was detailed in participant interviews as a

forceful individual effort that draws one forward. One study participant re-counted the negativity of the time after diagnosis and his efforts to move from this despondent time. He recalled this time stating, “It was a real unhealthy situation for me. It (the diagnosis) affected me. It (the diagnosis) plays with you. It’s there. I looked down at my wedding band and I said, I have to get through this” [B.16.4]. Another participant spoke of his personal resolve in a frank and straightforward response stating, “I had to move forward, you have to move forward, this is critical” [B.11.7]. This participant spoke these words after recalling his experience after the diagnosis of cirrhosis, in the *doing nothing* category, where he had remembered an emotionless and straining time with the words, “I was numb, I was trying to remain normal” [B.11.5]. Another participant spoke candidly and demonstrated this property of *needing to move on* with a simple and direct statement, “you have to move on” [A.7.4]. This participant was attesting to his efforts of moving from the negative emotional impact of this diagnosis. The thrust forward was grounded within the individual and this charge is personified in the participant response, “It was up to me. It was on me” [A.9.6]. This statement was made in the context of this participant’s recollection of *wanting something else*, with the acknowledgement that to be in a different place would be because of a distinct personal energy.

This phase of the process was followed by a time when the individual *works through the diagnosis of cirrhosis*. It is the time in the process where one went back to the primacy of family teachings and relied on their faith in God. These two elements enabled the individual to *work through the diagnosis of cirrhosis* to where they could assimilate this diagnosis into their life and *accept it*.

Working through the diagnosis of cirrhosis

Individuals described how they *work through the diagnosis of cirrhosis* by first reflecting on primary values and having faith in God. Individuals initially went back to what was imparted by family and how they were raised. These teachings included dealing with the unfavorable and facing these life events in a straightforward and robust manner. The initial property of this category is, *how I was raised*. This property is illustrated with the following accountings. One participant articulated the remembrance of the teachings of his mother stating, “I went back to what my mother taught me, never worry about things you can’t control” [B.11.8]. Other participants echoed this sentiment with the recall of the family credos of values that continued to influence a personal power and stamina in difficult situations. This outlook was captured in the following participant responses, “It was how I was brought up. You have to tough it out” [A.5.9] and “It’s from my dad, he’d say you have to face things head on” [A.10.11]. The beliefs and attitudes imparted by early family teachings had a lasting personal effect that supported the individual with the life encounters that were hard. This view was personified with a participant stating, “It is how I was raised, it’s my philosophy, when something comes up, deal with it” [A.8.10]. Another participant spoke in realistic terms. They talked of their current state, rather than going back and wishing for something different. This position was depicted with the participant response of, “You have to deal with cards that you are deal.” [B.13.7].

Many participants spoke of relinquishing the fear of the unknown by relying on a higher power and having faith in God. The second property of this category was *trusting in God*. In one interview, the participant portrayed this trust in stating, “He is only going to give me what I can handle” [B.15.5]. Another participant, who was 76 years old, spoke of daily prayer and the belief

in God's help. Her words were firm and expressive, "I get down on my hands and knees and pray to God." [A.10.8]. Others spoke of the personal power of prayer and *trusting in God*, which helped them to feel safe. This sentiment was characterized in the participant response of, "Prayerful. I am prayerful, I am protected" [B.17.6]. A striking example of this innermost confidence and reliance on a higher power was when one participant spoke the prayer, "Do you remember the story of where the guy is walking on the beach with the Lord and he looks down and all of a sudden there was only one set of footprints and he asked the Lord, why didn't you stick by me? The Lord said, I was with you, that is when I carried you. So, that is kind of it" [A.7.7].

Participants spoke of an active connection with God and that this effort was practiced regularly. These actions were deferentially stated by one participant, "I have been in contact with Him and I stay in contact with Him" [A.5.6]. Another participant simply stated, "I pray the rosary every day" [A.9.8]. This relationship and *trusting in God* sanctioned a personal acquiescence, where one was able to begin to let go of the fear of an uncertain future. This yielding to the unknown was clearly stated by a 55 year old male, who had been diagnosed with cirrhosis two years before. The context of his statement was in his speaking of knowing that he was not in control of this diagnosis. He stated, "It's up to the guy upstairs, He's the One with the final say" [A.5.6]. Another participant spoke of an alike feeling with the statement "you can't feel it (cirrhosis). I am at the Mercy every day" [B.11.7].

This stage of the theory precedes the point of when one can *accept it*. In this next phase of the process, individuals spoke of acceding to the actuality of having the diagnosis of cirrhosis. When this reality was acknowledged by the individual, they had a foothold to begin to distance

themselves from the emotional unease that accompanied this diagnosis.

Accept it

In being able to *accept it*, individuals asserted that they recognized that they had to assimilate this diagnosis into their life. It was within this stage of the process that one became less attached to personal desires and more open to the indefinite. The properties of this conceptual category were *surrender* and *not being in control*. Participants in this study spoke of conceding to what was certain. There was a strong recognition of what was fact. In the first property of this category, there was an acknowledgement that life in this world is finite. This *surrender* to what is, was stated directly by one participant, “I know that you don’t live forever” [A.4.9]. This time of *surrender* was described as a period of personal release and being able to let go. This sentiment was personified in the participant responses of, “what is going to happen is going to happen” [A.3.6] and “what will be, will be” [B.6.6]. Other participants gave an added perspective to the of the ability to *surrender* with the words: “I gave up worrying, what’s going to happen is going to happen” [A.5.8] and “what is meant for me is meant for me. That’s how I look at life” [B.12.6].

Within this stage of the process, one not only assumed the immediate reality, but recognized that they will forfeit more. One was resigned and rational. They had the ability to relinquish those elements of the disease process that they had little influence over. The second property of this category was *not being in control* and was expressed in the participant response, “I am going to have to live with the restrictions that the disease imposes” [B.13.8]. Another participant described this period of *not being in control* and the awareness for an adverse unknown, with the response of, “you have to accept it, because the tests are going to get worse”

[A.6.10]. Other participants spoke of being aware that they had little personal influence on what was to come. This attitude was evident in the participant response of, “I know that this is out of my control, there is nothing that I can do about it” [A.9.7]. Another participant echoed a similar reaction with the words, “...out of my control, I’ll do what I have to do, but it’s out of my control” [B.11.6]. A poignant depiction of the property of *not being in control* and the ability to relinquish what one does not have power over, was from one participant when he stated, “the serenity prayer, this is critical” [B.15.8].

When one *accepts it*, they continue with a forward momentum. There is an easement of the ongoing worry and anxiety. One is able to differentiate from negative emotions and *not worry about it*. This category is addressed in the next section.

Not worry about it

In this portion of the process, individuals have reached a point where they are able to *not worry about it*. They are capable of quieting the prevalent emotions of apprehension and fear. Participants described developing this ability, by being able to selectively not think about the diagnosis of cirrhosis. The first property of the category was identified as *stop dwelling on it*. This was a time where individuals made a conscious and deliberate choice to *not worry about it*. They had gained the ability to suppress negative emotions. This property was illustrated in the plain spoken words of one participant who stated, “I pretty much bury it in the back of my mind” [A.8.7]. A similar expression of this property of *stop dwelling on it* was repeated in the response of, “I block it out of my head” [A.3.10]. Participants spoke at length about not being consumed with the thoughts of this diagnosis and having it always first on their mind. The participant statement of, “I try not to put the cirrhosis at the forefront” [A.9.7] demonstrates this capability

to stifle that which had been daunting for them, along with a personal resolve. Another participant repeated this ability to dampen undesirable emotions with the words, “I put it (the diagnosis) up on a shelf. It is silent to me” [B.15.4]. This ability to *stop dwelling on it*, enabled one to relinquish the emotional consequence of worry. This property was reflected in the responses of, “I learned to stop worrying” [B.13.8] and “It bothers me, but I try to not worry about it” [B.17.9]. Another participant repeated this effort with the words, “I try not to dwell on it. I don’t let it get the best of me” [A.10.6].

Individuals spoke of believing that, if they were able to maintain the ability to *stop dwelling on it*, that they would be able to prevent further emotional regression. There was a personal insight and comprehension by participants that they understood the negative effects of persistent and constant worry. The second property of this category was *not getting depressed*. Participants recognized the deleterious effects of continued unease. One individual stated this perception with the statement of, “If I focus on my disease, it will really get me down” [A.6.6]. Another individual spoke in similar terms, stating, “If you worry about it, you will get depressed” [B.14.9]. One participant communicated not only this understanding, but a perceptiveness that one can control emotions that weaken stamina, with the words, “You cannot get depressed, you cannot let that happen” [B.13.7]. Another individual perceived the connection between the ability to be optimistic and *not getting depressed* stating, “I try to be positive and not let it get me down” [B.16.5]. One individual re-spoke of family teachings, as in the *working through the diagnosis of cirrhosis* category. He spoke of how these teachings helped to alleviate the burden of worry, remembering what his mother had spoken in years past, “It’s what my mother said, you have to have a positive attitude. I go back to that all of the time” [A.7.6].

The final conceptual categories of the theory describe how one lives with the diagnosis of cirrhosis. In this phase of the process study participants portrayed the importance of having the support of others and *being in good hands*, which enabled them *to do everything that they can to care for themselves*, putting them *in a good place*, with *having the other side of the coin* and being able to *live day by day*.

Being in good hands

Participants spoke of *being in good hands* with having caring individuals in their life and the influence that this had on their well-being. Individuals spoke of the influence of both loved ones and their health care providers. The devotion of loved ones provided the individual with support and an existential human bond. The first property of this conceptual category was *connection with others*. Individuals spoke at length about the primacy of their relationships with family and friends. The response of, “my family has helped me more than anything” [B.16.9] demonstrates the importance of these personal relationships. Others spoke about the significance of friendships. The value of these relationships was appreciated in the participant responses of, “I am so fortunate to have such caring people in my life, [A.9.9] and “my family and friends have been just wonderful” [B.11.8]. Individuals spoke of the strength they drew from long term and devoted relationships. The caring actions of loved ones provided the individual with more than assistance. There were feelings of delight and joy. One participant was descriptive of this support that she received from her spouse, stating, “Oh my God, my husband, he stepped up to the plate. He’s so supportive, it’s a nice surprise” [B.13.11]. Another participant spoke in simple terms with the words, “my wife, thank God for her” [A.9.9]. In addition to the individuals receiving support, there was a mutual benefit for the relationship. A specific response that embodied this reciprocity

was, “All the worry and emotion, this has brought us closer. After 23 years, this has brought us so much closer. It’s unbelievable” [A.7.8].

Study participants spoke at length about the attentiveness that they received from their health care providers and the intense personal impact this care had on them. The second property of this category was *the influence of provider care*. All individuals in this study spoke about the connection they had with their health care providers and the benefit that they derived from this relationship. This benefit was both a connection with care and a relationship of trust. One participant articulated these attentive actions of their health care providers in stating, “the care from the doctors and others, it has been terrific, it made all of the difference” [A.5.10]. Another participant spoke of this sentiment in a similar way, with the words, “the level of care, the attention they gave me, it made all of the difference” [B.2.7]. Participants portrayed their relationship with their provider as one of faith and confidence. One participant explicitly described this experience as, “Those simple words, you are going to be ok, don’t worry, you are not going to die now. Those simple words are so important. It’s been two years since I heard that, but at the time you hear it, you take it to the bank” [B.14.10]. Another participant stated similar emotions with the response, “she (physician) told me everything is going to be ok, don’t worry.” [A.9.8] This provider relationship held a deep bond and included affection. One individual had the straightforward retort of, “Dr. T, I just love her” [B.3.7]. Another spoke of all of those involved in his care, stating, “All the people at the university, I just love them” [A10.6]. Most participants spoke of their relationship with their health care provider as long-term. This was aptly portrayed with a participant stating, “she’s (physician) my friend for life” [B.7.8]. Others again spoke of God, as in the *working through it* category. At this point in the process,

individuals had faith that God was working on their behalf. One participant believed that his doctor was a gift from above and said, “God provided me with the best doctors and care” [A.6.8]. Another participant had similar words and stated, “God has been amazing to me, he provided me the university” [B.16.5].

When one was *in good hands*, this supported the individual *to do everything that they can for themselves*. This was a time of energy and purpose. One was dedicated to their health and committed to enduring.

Doing everything that they can for themselves

In this phase of the process, when one was able to *do everything that they can for themselves*, participants described their actions of being a self-champion and having a powerful personal commitment to sustain. The properties of this category are *well-being* and *determination*. In the first property of *well-being*, individuals spoke of working to maintain health. They talked about staying physically active and making this a part of their individual routine. There was a private and personal pledge to these actions. Responses that relayed these actions were articulated in the words, “I stay active” [B.11.7] and “I walk every morning” [A.9.5]. One participant simply stated, “I keep on. I keep on trying” [A.6.7]. Participants reached out to others for assistance. This effort was exemplified with the participant response of, “I joined a support group” [B.14.7]. Participants committed to the tasks of their health care, with an individual testament of, “I did everything that they wanted me to do, if they wanted blood work I went all the way down to the university, I took a train to the university” [A.2.9]. Within this property of *well-being*, participants acted to protect and extend the functionality of their liver. This was particularly articulated by one participant in the statement of, “I won’t do anything to

affect my liver, I mean if I broke my arm, I'd only take an aspirin" [B.15.6].

The second property of this category was *determination*. This property was characterized by a prevailing personal force to endure, which is illustrated in the following participant statements, "I am not going to give up" [A.9.6] and "I am determined to stick with it" [B.11.8]. Individuals compared their struggle with this diagnosis to fighting an enemy. One participant articulated, "I am fighting a long battle" [A.5.6]. Another participant used similar words of combatting this diagnosis, but added the perspective of a personality trait of being willful. He stated, "It is my 'hard headiness.' I want to fight this" [B.13.8]. Within this property of *determination*, there was a belief that this personal power would forestall the inevitable. This was illustrated with the participant statement of, "I am not ready to leave this world yet" [B.14.9].

As one was able *to do everything that they can for themselves*, this *puts them in a good place* that is both hopeful and productive. This was a time where one has regained a self-assurance and the ability to enjoy life events.

Being in a good place

In this phase of the process, the individual recovered some personal control and was able to look forward to the near future. The properties of this category were *being confident* and *being expectant*. In the first property of this category, *being confident*, participants talked of having a personal positive position which influenced individual control. This ability of *being confident* was attributed to having a certain positive attitude. This outlook was reflected in the participant response of, "power, it equals a positive mental attitude" [A.7.8]. Another individual had very similar words, "it is all with your thinking, positive mind, positive thoughts, positive results" [A.2.6]. This optimism was reiterated in the response, "I am in a good place right now, my liver

is still functioning and my kidneys are good, I can still do a lot of things that healthy people can't do" [B.16.4].

In the second property of this category, that of *being expectant*, individuals believed that they had at least a near future. This expectation was visible in the participant response of, "I believe that I have a few more years left" [A.6.9]. Another participant spoke of this hopefulness with the words, "I have stopped numbering my days" [B.12.8]. Individuals had recovered a capability to not only look ahead, but to desire these occurrences. This sentiment was portrayed with the words, "I look forward to things, I look to the future. I think...I am going to be OK" [B.14.10]. Within this category property of *being expectant*, in addition to the ability for a future outlook, there was energy. One participant keenly articulated this feeling with the response, "I'm a happier person now, let me give you an example. I'm doing my bucket list. I just took a two-week vacation" [A.7.10].

Being in a good place favored the individual in ***having the other side of the coin***. This was a time in the process when individuals relished what they have. They made associations with others. Participants were considerate of others in this phase of the process and imparted of themselves to others in giving ways. They worked to connect with others and share their experience with this diagnosis.

Having the other side of the coin

In this phase of the process, ***having the other side of the coin***, participants made comparisons to others who were in poorer condition, spoke of appreciating others more, being more compassionate, and having the ability to give to others. It was a time that one has happiness, enjoyment, and gratification. The properties of this category were *being fortunate*,

being kindhearted, and *telling their story*. In the first property of the category, *being fortunate*, individuals spoke of making downward comparisons to those who were in more difficult or worse situations. These comparisons were intentional. One participant stated, “I look at others, even my wife said you’re better off” [B.15.11]. Another individual looked back in his life for this personal evaluation and said, “I remember the kitchen table of old people, all the pill bottles. I’m not taking as much as others, so in the end, I’m better off” [A.7.8]. One participant was purposeful in reading the stories of others and shared, “I go on-line and read stories of people and how bad off they are and it’s heartbreaking and I know how lucky I am, even though I have this disease, how lucky I am” [B.11.8].

In the second property of this category, participants spoke of *being kind-hearted*. This was a time of empathy and generosity. One individual shared that, “I am a compassionate person, but more so now” [B.11.9]. Another participant spoke about, “all the trials and tribulations that I went through, it just made me appreciate people all the more” [A.6.7]. Individuals spoke of a mutual benefit from giving to others. These acts included driving individuals to doctor appointments, volunteering at church events, and becoming active in support groups. One individual stated this experience with the statement, “the ability to give and appreciate giving, this is joy, this is true joy” [B.12.9]. Another participant echoed this sentiment, revealing, “I’m helping them, more important, I feel wonderful about it” [A.3.8]. The reciprocity that one experienced in giving was characterized in the participant statements of, “I get more back than I give” [A.7.9] and “this doing for people helps me, it helps me be more understanding” [B.14.10]. A strong participant expression of this personal life position was, “When I used to teach, I taught the works of Bob Stone. ‘That which you give freely and without thinking of reward will come

back to you 10,000 fold” [A.7.9].

The third property of this category was *telling their story*. Individuals expressed the desire to help others by telling their story. One participant simply stated, “I want others to know this” [A.3.9]. Another participant spoke of having the diagnosis of cirrhosis and imparting her experience with the words, “I talk about it. I am not ashamed. Well, I have it (cirrhosis)” [B.14.5]. Others told of wanting a benefit to their experience with cirrhosis. One participant stated, “I tell my story for others, to let them know what happens if you don’t turn your life around” [B.12.6]. Another individual reiterated this sentiment with, “I tell my story, so others can see, this doesn’t have to be you” [A.2.6]. Other participants repeated this response with the words, “there are choices, they can make different choices” [B.15.9], “they don’t have to go through what I’m going through” [A.2.8], and “I use my church as a platform to tell others, to help others” [A.8.8].

This category preceded the final phase of the basic social process of how one lives with diagnosis of cirrhosis which is *living day by day*. In this final phase of the process, one had incorporated the diagnosis into their life and was able to continue on and live their life.

Living day by day

The final category of the basic social process of how individuals live with the diagnosis of cirrhosis was *living day by day*. The properties of this conceptual category were *being composed* and *steadiness*. This was a pragmatic time for the individual, where one was able to balance the present with an indeterminate future. Participants spoke of living, despite holding a diagnosis that was life limiting. The category property of *being composed* was articulated in the participant response of, “I go on and try to live my life, I live as normal as possible” [A.10.9].

Others spoke of having time left and a remaining vitality. These emotions were embodied in the participant responses of, “I’m still filled with life” [A.2.4] and “I still have some life left in me” [B.17.8]. Another participant spoke with the explicit words, “I will enjoy what time I have left” [B.16.7].

The second property of this category was *steadiness*. Individuals spoke at length about being able to focus on the present day. In this second category property of *steadiness*, individual descriptions were strong and precise. Participant responses were focused on the proximate and this was illustrated with the statements of, “I try to take it one day at a time” [B.15.9] and “I just live day by day” [B.13.10]. Individuals spoke of living whole-heartedly and without the expectation for a future measured time. This attitude was represented in the participant response of, “I keep on living, one day at a time” [A.5.8]. Another participant spoke comparable words, with the statement, “I can usually do what I want to do, I stay hopeful, I want to live for a longer time, I go on and try to live my life, I take it one day at a time” [B.14.8].

The categories and the relationship between the categories of this theory are displayed below. The basic social process of how individuals live with the diagnosis of cirrhosis begins with:

Having a damned day, which is followed by ***preparing myself for the worst***.

These two categories combine and place the individual in a stationary state where they ***do nothing***. This component of the process sets the condition for the individual to ***move forward***, when they can ***work through it*** and ***accept it***, to where they are able to stop ***worrying about it***. When one has the support of others and is ***in good hands***, this enables them to ***do everything that they can for themselves***, putting them in ***a good place*** and ***having the other side***

of the coin to where the individual is able to *live day by day*. The core category, *It is always the monkey on my back*, reflects the ever present strain and worry that is associated in living with the diagnosis of cirrhosis. This process is illustrated with a diagram in Appendix G.

In the final section of this chapter, the investigator's adherence to study rigor and the components that demonstrate this attention are discussed.

Study Rigor

The grounded theory method produces a middle range theory, that is inductively derived from data systematically obtained from research participants. Data analysis is conducted simultaneously with data collection, utilizing the constant comparative method where emergent categories are verified. The investigator relied on memoing, which was utilized throughout the data analysis process, to aid in the recall of impressions and interesting ideas and to maintain exclusivity of conceptual codes and categories. This process supported the investigator to determine the theoretical structure. The end result of this work was a substantive theory that provides an explanation and prediction of behavior. This enhanced perspective enables one to have an added capacity for influence in the situation. Additionally, the theory generated through the grounded theory method provides guidance for future research (Glaser, 1978; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Speziale & Carpenter, 2007).

This study upheld the expectations of rigor required by both the specific principles of grounded theory and the general principles of qualitative research. There are four explicit tenets of rigor that are applicable to the generation of grounded theory. They include that the theory must fit with the substantive area in which it will be utilized, the theory must be easily comprehended by those who will utilize the research work, the product must be sufficiently

generalizable across similar situations and conditions, and the theory must provide for at least partial control with the process studied (Glaser & Strauss, 1967).

The substantive theory developed from data generated in this study tells of the basic social process that one undergoes after being diagnosed with cirrhosis and living their life with a threatening chronic disease and illness. This theory was inductively developed from the personal accountings of those that have lived this experience. The usefulness of a theory is judged by how it was generated and the process that was utilized (Glaser & Strauss, 1967). There is a logical consistency in the process that emerged from this research. Categories that emerged from the data were compared, and those that had similar properties or connections were combined into broader categories. This data reduction resulted in categories having a broader scope with a rich and dense depiction of the phenomenon (Glaser & Strauss, 1967; Speziale & Carpenter, 2007). The structure was developed from categories that have a natural and inherent fit. All transcripts were re-reviewed, as the theory developed, to assure that the theory appropriately fit with the data. The theory is reported with clarity, in language that is easily comprehended, making practical application straightforward. The conceptual categories are well defined and distinct which makes hypothesis testing in quantitative research possible, because the concepts can be operationalized. And lastly, the category findings are abstract, which allows for application across time and conditions. The ability to test this theory and apply the findings across time and conditions, meets the criteria of assessing the scope of this research work (Glaser & Strauss, 1967).

The standards of rigor pertaining to qualitative research in general include the principles of credibility, dependability, confirmability, and transferability. Credibility is defined as the

trustworthiness of the study (Chiovitti & Piran, 2003). In this study, credibility was maintained by this investigator accurately and faithfully reporting participant responses. These responses are illustrated throughout the research work and these statements support the properties of the conceptual categories that emerged from the data. Information was collected until data saturation was achieved. The findings of this study represent the reality of the study participants who have lived this experience and this process is evident in the interviews conducted for this study (Glaser & Strauss, 1967; Lincoln & Guba, 1985).

Dependability is equated to the stability of the data (Lincoln & Guba, 1985). This criterion is met when credibility of the study is confirmed (Speziale & Carpenter, 2007). Furthermore, the theoretical structure that emerged from this work is practical and sensible. It explains what one has gone through, predicts what will happen in this process, and interprets what is happening in the area of this specific study (Glaser, 1978; Glaser & Strauss, 1967). Additionally, this investigator reviewed data analysis, verified codes and evaluated the theoretical structure as it developed with the principal investigator of this dissertation. During these meetings, perspective was gained on alternative explanations, and guidance was received on category fit and conceptual structure.

Confirmability refers to the ability of another researcher to have the ability to follow the methods and conclusions of the original researcher (Chiovitti & Piran, 2003). This criterion was maintained in this study by the establishment of an audit trail, adherence to the constant comparative method of data analysis, and the end product of a theory that is applicable to practice (Glaser, 1978; Lincoln & Guba, 1985). The audit trail for this study began with initial journal entries on preconceived ideas and potential bias that might influence the investigator's

interpretation of findings. This was followed by notes during each interview on ideas, impressions, and instances of thought-provoking responses. The investigator continued with journal entries that documented thoughts on data fit and connections, and areas where more information from participants needed to be provoked. Data collection continued until category saturation was achieved, and without premature closure. There was a preservation of taped audio study interviews, transcriptions, theoretical notes, and the accounting of the process of data reduction and conceptualization. The audit trail included the dates and times of interviews and analysis, the theoretical memos that connected data to categories, and those conceptual categories that shaped the theoretical model. This documentation supports analytical accuracy, theoretical decisions, internal coherency, and permits future scrutiny (Burns & Grove, 2009; Glaser & Strauss, 1967; Sandelwoski & Barroso, 2002).

Transferability is determined by the work being applicable to others that hold the diagnosis of cirrhosis (Glaser & Strauss, 1967; Lincoln & Guba, 1985). In this study, conceptual categories were inclusive and substantial, providing a wide range of information for others. The conceptual categories within this theory provide an explanation of the basic social process of how one comes to live with the diagnosis of cirrhosis. The category findings are abstract, which allows for application across time and conditions. This research work is transferable to others who are in similar situations as those participating in this study. This would include individuals who has been given the diagnosis of cirrhosis at multiple time points, which could include the inpatient setting or private physician office. This theory is relevant to individuals with the diagnosis of cirrhosis who are at different time periods of living with this diagnosis. These periods would include the early, middle, and the final stages within the process of this theory.

And lastly, this theory could be tested in those who hold this diagnosis at different time points.

Summary

In this chapter, the theory model of the basic social process of how individuals live with the diagnosis of cirrhosis was presented. *It is always the monkey on my back*, emerged as the core category, with twelve conceptual categories. Each of those twelve conceptual categories was addressed, and the properties of those categories was presented. Participant quotes and narratives provided expressive descriptions of the properties associated with each of the conceptual categories that describe the processes that one undergoes to live with the diagnosis of cirrhosis. The chapter concluded with a discussion of study rigor, trustworthiness of the research work, and the transferability of the theoretical framework to others who are in a similar situation, as those who participated in this study. In the following chapter, the study findings are discussed as related to previous literature, new findings in nursing knowledge are identified, and implications for practice, education, administration, and research are addressed.

CHAPTER 5

DISCUSSION

The purpose of this chapter is to discuss the key findings of this study, which investigated the process that individuals undergo to live with the diagnosis of cirrhosis, and compare the results of this study with previous theoretical and research findings. The chapter begins with a discussion of the basic social process and the core category that emerged from this study. This is followed by a presentation of the twelve conceptual categories and the specific properties of each of those conceptual categories in the theory. These findings are discussed and either directly aligned or contrasted with previous scholarly work. A discussion of the unique findings from this study follows this section. The chapter is concluded with a discussion of the strengths and limitations of this research along with recommendations for future application in nursing research, practice, administration, and education.

Basic Social Process

The process of living with the diagnosis of cirrhosis that emerged from the data, is a linear process that begins with *having a damned day*, when individuals are told of their diagnosis. This is followed by a period where individuals are *preparing themselves for the worst*. These two categories combine to place the individual in a state where they *do nothing*. This component of the process sets the condition for the individual to *move forward*, when they can *work through the diagnosis of cirrhosis* and *accept it* to where they are able to *not worry about it*. *Being in good hands* supports the individual *to do everything that they can for*

themselves, putting them *in a good place*, where they *have the other side of the coin* and are *able to live day by day*. The core category that emerged from this study was, *it is always the monkey on my back*. This core category was a prevalent and continual event across all twelve categories and illustrates the fear and concern that individuals had for what may lie ahead for them. The core category is discussed in this next section and is followed by the twelve conceptual categories of this process.

It is always the monkey on my back

The core category that emerged from this study was, *it is always the monkey on my back*. Participants in this study repeatedly told of their private worry and strain regarding anticipated negative health events. This individual burden has been articulated in the literature as the psychological discomfort of illness, indirect suffering and temporal uncertainty. The psychological discomfort of illness has been described as the pressure to endure, concern, worry and the loss of an expected future (Morse & Johnson, 1991; Woods, et al., 1993). Uncertainty for these individuals is temporal, where the timing of unavoidable and adverse events is not known. When one is in a situation where harmful events are unpredictable, there is an unrelenting apprehension and foreboding (Monat, Averill, & Lazarus, 1972; Mishel, 1988; Mishel, 1990).

The conceptual properties, of the core category *it is always the monkey on my back* were, *persistent worry* and that this unease is *ever present*. Participants in this study endured the concern and apprehension, with having a disease that has an unfavorable course, privately. This phenomenon has been previously characterized in the research works of Ekwall, Ternstedt & Sorbe (2007), Morse and Johnson (1991), and Meleis et al. (2000). In their study on women who had a recurrence of ovarian cancer, Ekawall, Ternstedt & Sorbe (2007), identified “living in

limbo” (Ekwall, Ternstedt, & Sorbe, 2007, p. 270), as the core variable of that research work.

The researchers’ contended that this state illustrates the condition of continued solitary strain and stress when one is persistently on the threshold of the unknown. With the diagnosis of cirrhosis, this unknown is the uncertainty of the timing of a decline in liver function and decompensation. Morse & Johnson (1991) asserted that for those who are in the situation of having a chronic disease and illness, with periods of only temporary stability, that there is never closure for these individuals, which is consistent with the core category of, *it is always the monkey on my back*. Meleis, et al. (2000) would differentiate this experience as a multifaceted health-illness transition, which is predisposed to parallel and influencing events, and will require the individual to endure cumulative loss, experience the emotional reaction of fear, and be confronted with the ongoing test of incorporating the disease and illness experience into their life. The experience of living with the diagnosis of cirrhosis closely aligns with these findings where this diagnosis is *ever present* and the *persistent worry* that individuals experience in having a diagnosis that has an adverse and unpredictable course.

In the next section of this chapter, the twelve conceptual categories and the specific properties of those categories will be presented. These categories and properties are related to prior scholarly work. This section is concluded with both the key and unique findings in this research study.

Having a damned day and Preparing for the worst

In the beginning stages of this basic social process, the findings in this study demonstrated that there is an initial, intense, negative, private, and emotional reaction. Participants told of being worried and fearful in having a disease that was both incurable and life

limiting. They spoke at length on deliberating about death and the trepidation of getting liver cancer.

The two initial stages of the process *having a damned day* and *preparing for the worst*, closely align with the previous theoretical and research work on coping and uncertainty. It has been proposed that aspects of the illness experience produce tremendous disorder at two time points, that of diagnosis, and again in later stages of the disease (Woods, et al., 1993). This initial cognitive assessment and emotional response to a serious, long term diagnosis set the platform for future coping actions. The more complex the occurrence, the more difficult it is for the individual to exert a personal control and find meaning with the event. When these events are coupled with an anticipated negative trajectory and an erratic illness course, there is an added ominous intensity (Corbin & Strauss, 1991; Lazarus, 1991; Lazarus & Folkman, 1984). The finding in this study that align with this literature is the immediate realization of participants that this diagnosis is unfavorable, not curable, and permanent.

As one undergoes the process to live with the diagnosis of cirrhosis, they are being confronted with an undesirable external event that will require them to undertake a significant internal process, which will result in a change over time. This has been identified as a health-illness transition (Meleis, et al., 2000). With the diagnosis of cirrhosis, there was a powerful initial awareness of a future modification. The findings in this study, of this arresting primary response to the diagnosis of cirrhosis, demonstrate the properties of change and difference in the study findings of the individual's response to hearing that they have the diagnosis of cirrhosis. The conceptual categories of *having a damned day* and *preparing for the worst* express the unexpected and abrupt realization that those who bear this diagnosis have an unforeseen and

altered future. These properties of change and difference have been identified as specific characteristics of the transition process (Meleis, 2007).

When these elements of the transition experience are coupled with uncertainty and a negative trajectory, there is the added burden of stressful responses and difficulty in employing coping strategies (Lazarus, 1991; Selye, 1978). An individual's initial response to a demanding event has been identified as a primary appraisal (Lazarus & Folkman, 1984). This primary appraisal closely associates with the findings in this study with the conceptual category of *preparing for the worst*, and the properties of that category. This was the time when the individual was assessing the immediate peril and threat. This reaction was influenced by the magnitude of the incident, the extent of control one had, and the mandated adjustments that would be required. In the findings from this study, the conceptual properties of *knowing it was bad* and being *shocked* support this previous theoretical work, and are the primary appraisal.

Individuals additionally contended with the *fear of getting liver cancer* and *prepared themselves for death*. Similar properties have been documented in both the works of Kralik (2002) and Nordenfelt (1995). Women who were diagnosed with a mid-life chronic disease described the initial turmoil with the diagnosis as a time of vulnerability and a loss of optimism (Kralik, 2002). The apprehension that one has with chronic disease is both persistent and pervasive. The individual experiences something different than they had anticipated (Nordenfelt, 1995). The findings in this study, of individuals speaking of a passing future and knowing that they have been given a life limiting diagnosis, align with this previous work.

Individuals who have been given a complex diagnosis, that is associated with events that will be unpredictable, experience uncertainty. This condition is the result of being in an

unstructured situation and without a frame of reference. One is in an emotional state where they are unable to select options or take action. Hope, at this point, is absent for the individual (Mishel, 1988; Morse & Penrod, 1999). The findings in this study, at this phase of the process, replicate these previous findings in the participant descriptions of *preparing for death*. The specific *worry of getting liver cancer*, is a unique finding. However, this finding does align with the specific research question investigated in this study, with liver cancer being the end result for many with this particular diagnosis.

The first two conceptual categories of this process, that of *having a damned day* and *preparing myself for the worst*, combine and place the individual in a stationary state where they *do nothing*. The data from this study describe this time as a period of isolation and inactivity.

Doing nothing

In this phase of the process, individuals were isolated and quiescent. It was a private period of sequestration, seclusion, and inertia. Bridges (1980) referred to this time as the in-between period and it was a critical and essential point in the transition process. It was a private time of isolation and solitude where the individual bears the loss and undergoes an inner personal change that enables one to let go and to move on.

The conceptual properties of this conceptual category were *corporal immobility* and *isolation*. These phenomena were recognized in the early works of Bridges (1980) and his contributions to the development of the concept of transition. One is in an indeterminate state. This is a key element in the transition process. It is the time that one is bearing through an internal chaos and it is within this in-between time that one is able to let go of the old and find the new. A critical inner change is taking place (Bridges, 1980).

This phenomenon has been identified in Mishel's reconceptualization of uncertainty (1990). The theorist purports that there is an unobservable state where the individual undergoes a restructuring of meaning and values. One is transitioning from a particular perspective in life to another, where it is recognized that uncertainty is perpetual.

Hogan & Schmidt (2002) portray a time of withdrawal from others, within the grief process. It is a time that concurs with the loss that one is undergoing, where self-assurance and self-reliance with the situation is absent. The findings in this study of *isolation*, align with this previous work, where one secludes themselves from others and remains in a private and personal place.

Kralik (2002) studied the effects of a threatening chronic disease diagnosis, and living with chronic illness, in middle aged women. The researcher identified this personal quiet time as a period of extra-ordinariness. This private silent time was when the individual faced the personal struggle that followed a profound life occurrence. It was a state of estrangement, where there was sorrow for the loss of a former self. Confidence was tested with feelings of insecurity, there was a forfeiture of optimism and the capability to move forward was absent (Kralik, 2002). The conceptual properties of *corporal immobility* and *isolation* articulated in this study support these previous research findings. Within this reclusive component of the process, the individual undergoes an innermost realignment and emerges with the energy to *move forward*,

Moving forward

In the next phase of the process, *moving forward*, the data from this study portray individuals regaining incentive and drive. It was this personal energy that facilitates one leaving a private and barren place. This finding is closely associated with the earlier works of Hogan,

Morse, & Tason (1996) and Kralik, Visentin, & Van Loon (2006), which described this emergence from an intense sequestered period of distress and angst, with the capability to move on. The findings of this previous work are stipulated in this research as the essential personal energy that is needed at this point in the process. It is this push that pulls the individual out of a lone and solitary time.

The conceptual properties of this phase of the process were *wanting something else* and *needing to move on*. These properties have been conveyed in the literature with the concept of transition. The process of any major health-illness transition involves an ending of life as one has known it, facing a new beginning, and an internal process where one engages a personal course of action. The resonance of one's spirit comes when one has had a pause and the time to grasp the change. It is then that one can emerge from this inner disorder and confusion with renewed energy (Bridges, 1980; Schumacher & Meleis, 1994).

This period has been defined by Kralik (2002), as a time of ordinariness. It is the phase when one is restructuring their life with illness. This transforming experience begins with a dynamic state and requires a prodigious personal effort. Identity is being reconstructed and one is able to move on (Kralik, 2002). These conceptual properties of *wanting something else* and *needing to move on* parallel these previous findings.

This phase of the process was followed by a time when the individual *works through the diagnosis of cirrhosis*. It was a time in the process, where one went back to basic family teachings and relied on their faith in God. These two elements enabled the individual to *work through the diagnosis of cirrhosis*, to where they could assimilate this diagnosis into their life and *accept it*.

Working through the diagnosis of cirrhosis

In the next phase of this process, the data from this study depict this period of *working through the diagnosis of cirrhosis*, as a time when one remembered family values and turned to their faith in God. These family values were the earlier life teachings of how to deal with difficult life events. In this part of the process, individuals drew from these prior teachings of family to assuage the emotional disorder and instability that they were undergoing. This finding closely aligns with prior scholarly work. One's emotions are grounded in the attitudes and viewpoints to which they are committed and to those teachings that are important to them (Blumer, 1969; Lazarus, 1991).

This asset, of being able to draw from one's relationships in life, has also been described by Stanton, Collins, & Sworowski (2001) as the personal and interpersonal context that influences the individual in both the appraisal of the situation and the employment of coping activities. The findings in this study depict this point in the process as the place where the individual begins a secondary appraisal of the event. They are determining personal control. This is the commencing point of implementation of higher level coping processes, which aid the individual to manage emotion and problem solve (Lazarus, 1991; Lazarus & Folkman, 1984; Stanton, Collins, & Sworowski, 2001). The findings in this study align very closely with this previous theoretical work.

The conceptual property of this category of, *how I was raised*, has been articulated in the literature regarding the concepts of transition, meaning, and coping. Important characteristics that shape a transition experience include one's personal meaning and outlook (Meleis, 2007; Schumacher & Meleis, 1994). The ability to attach meaning and find a place in one's life for the

untoward event, begins to allow the individual to have control and initiate a response versus being a direct reactor (Blumer, 1969). Self-confidence is influenced by both past personal connections with others and the ability to draw from those past experiences (Chick & Meleis, 1986). These two attributes support a more positive position for the individual. They have undergone a secondary appraisal of the situation and determined individual control and power (Mishel, 1988; Lazarus, 1991). It is when one ascertains this personal influence with the circumstance, that problem focused coping skills can be engaged (Lazarus, 1991; Lazarus & Folkman, 1984). More specific findings in this research work were how individuals went back to simple familiar idioms, from which they were able to draw continued strength and stamina.

Participants in this study spoke of their faith in God. Individuals relied on religious beliefs and faith for direction and bearing. It also gave them the ability to surrender fear and apprehension by trusting that a higher power has only given them what they can endure. This conduct has been identified in the literature as intrinsic religiosity, and it is categorized as a personal belief in God's role in one's health (Mishel, 1988; 1990). Mishel considered this a key component in an individual's experience with uncertainty. This personal asset reduced uncertainty by helping the individual to find meaning in the situation and structure an explanatory framework (Mishel, 1990). In this study, participants detailed their personal belief that a higher power was watching over them in the conceptual property of *trusting in God*.

An important characteristic of the transition process is when the individual has found meaning with the situation. Schumacher & Meleis (1994) contend that this subjective appraisal of finding meaning with the event lessens stress and influences a positive transition. This meaning that one attaches to the event is modified over time by an individual interpretive process

(Blumer, 1969). The findings in this study support these earlier findings, where individuals drew a personal fortitude from their religious beliefs. Findings in this study added the dimension of individuals being able to relinquish some worry and concern because of these personal spiritual beliefs.

This stage of the theory is followed by the phase when one can *accept it*. In this next phase of the process, individuals conceded to what was certain and begin to integrate this diagnosis into their life.

Accept it

As individuals worked to *accept it*, they moved into this portion of the process with ability to adjust effectively to the change and assimilate this diagnosis into their life. At this point in the process, the participants in this study were less enclosed by personal desires and more open minded to that which is indeterminate. One had found a place in their life for the event and was less consumed by it. These behaviors have been identified in the literature as the further implementation of secondary coping skills, which assisted the individual to integrate this untoward occurrence into their life. Individuals at this point in the process are able to behave purposefully, maintain a personal integrity, preserve goal congruence with more affirmative emotions, and uphold relationships (Lazarus, 1991; Lazarus & Folkman, 1984; Mishel, 1988; Roy, 1984; Stanton, Collins, & Sworowski, 2001).

The conceptual properties of this category were *surrender* and *not being in control*. The property of *surrender* has been identified in the secondary work of Mishel (1990) where it is postulated that when one accedes to uncertainty, there is a re-patterning of personal meaning and a new reality is formed. Bridges (1980, 2009) would identify this period as that of a transpiring

new beginning. One has let go of the old and re-defined their future. This change over time is the defining feature of a transition (Schumacher & Meleis, 1994). It is at this time one can begin proactive behaviors and implement the secondary coping action of information seeking, preparation and modification of activities (Lazarus & Folkman, 1984; Marineau, 2005; Meleis, et al., 2000). This point has been identified in the work of Hogan, Greenfield, and Schmidt (2001) as a personal growth, where the individual has reached a turning point in the process. The disorganization and difficulty with the situation has lessened and the individual begins to restructure meaning about themselves (Hogan & Schmidt, 2002).

The conceptual property of *not being in control* was identified in this research work. This is an added perspective to the conceptual category of *accept it*. Individuals in this study were able to accept the event along with the future deleterious consequences of the diagnosis of cirrhosis. This phenomenon was expressed by participants in the acknowledgement of a future decline in liver function and health. This property of *not being in control* has been identified as a component of personal growth, when one has been able to endure a life loss and depart from a desolate time to become different (Hogan, Greenfield & Schmidt, 2001).

When one *accepts it*, they can discern negative emotions and *not worry about it*. Individuals have developed the capability to curb the adverse emotions of apprehension and fear. This category is discussed in the next section.

Not worry about it

As one moves to this part of the process, they have acquired the ability to selectively not think about it. This capability permitted a tempering of the persistent emotions of apprehension and fear. This finding has been defined in the literature as a durable employment of secondary

coping skills. A distinct feature of being able to employ the higher-level coping skills of problem solving and having the ability to manage the emotions incurred by the stressor, is that this action is a conscious choice (Lazarus, 1991). This phase of the process continues to mark the integration of this event into one's life. There is a sense of control and one exhibits an emotional steadiness (Meleis, et al., 2000).

The conceptual properties of this category were *to stop dwelling on it* and *not getting depressed*. The ability *to stop dwelling on it*, has been similarly identified in the works of Folkman & Moskowitz (2004) on coping and the research conducted by Stanton, Collins, and Sworowski (2001) on adjustment. In the secondary appraisal of an untoward event, there is a cognitive evaluation that includes an emotional control. This directed coping attempt is a central issue in one's secondary appraisal of an alarming event. It is when one is able to assert some individual power with the situation and continue with a re-appraisal of the situation that is more affirmative (Folkman & Moskowitz, 2004). This conceptual property is further aligned with the concept of adjustment to chronic illness. It has been purported that when the individual has the personal attribute to exert an assenting emotional and behavioral influence with the situation, there will be a more favorable adjustment. This position favors the individual to respond to the event with cognitive adaptive efforts that serve to protect, restore, and improve one's current state (Stanton, Collins, & Sworowski, 2001).

The second property of this conceptual category was *not getting depressed*. This property is aligned with the theoretical works of personality traits (Bolger, 1990), grief and personal growth (Hogan & Schmidt, 2002) and adjustment (Taylor, 1983). The constructive personality trait of dispositional optimism affords the individual the attribute of self-discipline to hold a

positive affect (Bolger, 1990). The ability to avoid reflection on invasive and disturbing thoughts has been identified in the work of Hogan & Schmidt (2002) and found to be a positive element which contributes to coping, the engagement of social support, and personal growth. The capability of *not getting depressed* is comparable to Taylor's (1983) research work on adjustment in chronic illness. Taylor (1983) maintained that when individuals experience adversity and can respond to that event with constructive cognitive adaptive efforts, they are then enabled with a certain level of affirmative psychological functioning. This aids the individual in acknowledging where control is possible and to relinquish efforts where one has no influence.

The final conceptual categories of the theory describe how one lives with the diagnosis of cirrhosis. Individuals portrayed the importance of others and *being in good hands*, which enables them *to do everything they can for themselves*, putting them *in a good place*, with *having the other side of the coin* and being able to *live day by day*.

Being in good hands

The conceptual category of *being in good hands* associated with the support one received from an enduring connection with others. Individuals spoke at length about the love and support that they received from family, friends, and their health care providers. This care gave one the sustenance for self-care and personal commitment. These findings closely align with other theoretical work. In serious health illness situations, individuals need more from significant relationships (Morse & Johnson, 1991). As one moves through this phase of the process, an individual's response to the event is swayed by their personal connections and the mark of these influences. These relationships affect meaning, confidence and the ability to reach a healthy end (Blumer, 1969; Meleis, et al., 2000; Schumacher & Meleis, 1994). In addition to one's personal

relationships, there are the affirmative actions of health care providers that influence well-being. The acts of teaching, counseling, planning, care, and support shape a better and less uncertain position for the individual (Corbin & Strauss, 1991; Mishel, 1988; Nordenfelt, 1995; Walker, 2001).

The conceptual properties of this category of *connection with others* and *the influence of provider care* have been distinctly described in the research and scholarly work on the concepts of meaning (Blumer, 1969), uncertainty (Mishel, 1988), and transition (Meleis, 2007). The meaning that one attaches to an occurrence is derived from the social interaction that one has with others. The significance of this occurrence is modified over time through an interpretive process that is influenced by one's relation with others (Blumer, 1969). The social relationships that one has avert uncertainty by supplying feedback on the meaning of the event. These relationships additionally give the individual a sense of safety, where they have dependable support to help them to handle the event (Mishel, 1988). When one has the support of others, Meleis (2007) defines this as a positive condition that influences a transition experience.

Mishel (1988) identified the source of structured providers as influencing uncertainty. The theorist refers to credible authority as one of these structured providers. Credible authority is the degree of trust and confidence that a patient has in their health care provider. Mishel (1988) considered this relationship to be a key means in the prevention of uncertainty in illness. The confidence that one has in their health care provider augments predictability and supports one in interpreting their illness experience.

When one is *in good hands*, this places the individual in advantageous position to be able to *do everything that they can for themselves*. This category is discussed in this next section.

Doing everything that they can for themselves

When one has the advantage of support in both their personal relationships and their connection with their health care provider, they are able *to do everything that they can for themselves*. The participants in this study detailed this time as one of being a self-defender and having a powerful personal commitment to withstand. There was an intense undertaking to care for themselves and sustain. Morse and Johnson (1991) described this phase of the illness journey as the stage of striving to regain self. One commits to the struggle, pledges to goals, and regains individual command. The individual undergoes a purposeful redefinition of self which facilitates self-management (McEwan, et al., 2007).

The conceptual properties of this category were *well-being* and *determination*. The conceptual property of *well-being* is comparable to other research findings the literature. Taylor (1983) purports, in her work on adjustment to chronic illness, that with a recaptured sense of self and adeptness, that one can maintain affirmative coping abilities, which include goal directed behaviors. Taylor identified this stage of adjustment to chronic illness as gaining mastery with the situation, and that this mastery can be attained by other than control of the disease. Behaviors such as active participation in care are activities that demonstrate the ability of control. This mastery was associated with a sense of coherence, feelings of well-being, and enhanced coping abilities with difficult and challenging events.

Mishel (1988) identified the behaviors of mobilizing activities, in her theoretical work on the concept of uncertainty. These are the focused strategies that are employed when the situation has been assessed as manageable. The individual has replaced the initial confusion and

disorganization with acceptance of uncertainty and has an opportunity for personal growth (Mishel, 1990).

In a health-illness transition process, there are essential critical attributes to that course. The phase of engagement has been equated with the degree to which the individual is involved in the process. This is a proactive stage and includes the behaviors of information seeking and modification of activities (Meleis, et al., 2000). These behaviors are markers of the foundation for a healthy transition, when the aspect of role mastery is underway. This phase of the process has been defined as the achievement of skill and comfort with the new situation (Meleis, et al., 2000; Schumacher & Meleis, 1994).

The conceptual property of *determination* has not specifically been addressed in the literature on chronic disease and illness, but work that closely aligns with this property is that of Kralik, Koch, and Price (2004) and Hogan, Morse, and Tason (1996). An ever-present disease state and illness experience imposes a personal course that is entirely different than where one originally began. In addition to the employment of coping abilities and personal control, endurance in these situations entails forcing the boundaries that the disease and illness impose (Kralik, Koch, & Price; 2004). One has reached a point where they have come to terms with the loss and are able to maintain not only a present engagement, but have a future outlook (Hogan, Morse, & Tason, 1996). A distinct finding in this study was that this personal *determination* and behaviors of *well-being* would preempt further decline in liver function.

When one is ***able to do everything they can for themselves***, this ***puts them in a good place***. This is a positive and constructive time for the individual. One has gained confidence with the situation and is able to engage in life events that are pleasurable.

Being in a good place

Individuals in this study described this *being in a good place* as a time of individual control and power. This ability of individual power and control was keenly articulated in the sentinel work of Lazarus (1991) and one's coping abilities. Control in a stressful encounter is the prominent factor that influences coping. As one is able to employ the higher-level coping skills of problem solving and direct action, these actions continue to influence an emotional stability and afford the individual confidence and command with the situation. This continued upholding of secondary coping abilities determines endurance, regulates distress and helps the individual to handle the situation (Folkman & Moskowitz, 2004; Lazarus, 1991).

The conceptual properties of this category were *being confident* and *expectant*. One had perceived that they can manage the situation. The characteristics of *being confident* and *expectant* have been articulated in the literature on adjustment to chronic disease, coping, and the transition process. When one recovers confidence in the situation, there is a passing of the phase of estrangement and disintegration. This is replaced with stability and structured processing of information (Kralik, 2002; Taylor, 1983). Kralik (2002) identified this as a time when one has regained balance in their life and that there is a future direction. Folkman & Moskowitz (2004) characterized this as the capability to engage and maintain higher level coping skills of problem solving, information seeking and positive re-appraisal. These abilities regulate distress, support an emotional balance, and promote an overall healthier outcome for the individual (Folkman & Moskowitz, 2000; Folkman & Moskowitz 2004; Lazarus & Folkman, 1984).

Meleis (2007) imparts that a transition experience is more than a life event. A transition event requires an intense personal change in oneself. A marker of a healthy endpoint with the

transition event is role mastery. Role mastery has been defined as the time that one has developed self-confidence with the situation (Meleis, et al., 2000). When one has attained role mastery with the situation, this sanctions further personal control, which supports secondary coping skills. The sustained implementation of these coping skills promotes emotional control and endurance, along with supporting a positive endpoint in the transition experience (Lazarus, 1991; Schumacher & Meleis, 1994).

There was a vitality in this phase of the process. These individual actions closely correspond to the works of Morse and Johnson, (1991) and Wainwright, (1995). In studying the effects of chronic disease and illness, Morse and Johnson (1991) developed the Illness Constellation Model. This theoretical framework depicts the individual response to disease symptoms. The researchers identified the last stage of the model as that of regaining wellness. This is when one is no longer illness dependent. However, with the chronic and progressive diseases, this stage of the theoretical model is not long term or lasting (Morse & Johnson, 1991).

Wainwright (1995) identified transcendence as the ability of the individual to overcome the demanding aspects of awaiting liver transplant and to reach a positive end. Despite the encumbrance of living with end stage liver disease, individuals were able to go beyond this experience and maintain an optimistic future perspective. The conceptual properties of *being confident* and *expectant* aligns with the theoretical work of Wainwright (1995). Participants in this study portrayed this time as one of having a bright outlook, taking vacations and doing activities that they enjoyed. This productive phase of the process stations the individual for *having the other side of the coin*.

Having the other side of the coin

In this study, participants described this time as one of promise, optimism and generosity. Individuals viewed their position in a more constructive light. There was an emphasis on the favorable. This finding has been described in both the works of Taylor (1983) and Mishel (1988). In Taylor's (1983) research work on adjustment to chronic illness, the researcher identified the core category of this work as illusion. She defined this concept as the ability to view the known facts in a more positive light. The researcher maintained that it is this positive perception that affords the individual the capability to not only face the threatening situation, but to preserve despite setbacks (Taylor, 1983). In her work on uncertainty, Mishel (1988) defined illusion as the assurance that one forms from the appraisal of a situation, where the individual judges it to be an opportunity. Mishel contended that in these circumstances, one is more capable of retaining higher level direct coping skills and the end result of a healthy outcome more likely. It is in these situations where one calculates an opportunity, that hope can be maintained (Mishel, 1988).

Individuals described this phase of the process as when one made comparisons to those that were in worse condition. Participants also spoke of cherishing others more and being generous. The properties of this conceptual category were identified as *being fortunate*, *being kind-hearted* and *telling their story*. The findings of *being fortunate* and *being kind-hearted*, align with the previous theoretical work on coping (Lazarus, 1991; Lazarus & Folkman, 1984) and the concept of transition (Meleis, 2007; Meleis, et al., 2000). When one has been able to maintain higher level coping skills and these coping strategies are effective, reaching a positive end for the individual is more likely (Lazarus, 1991; Lazarus & Folkman, 1984). This healthy end has been characterized as the ability to resume normal and customary behaviors, uphold

important relationships and to continue on with purpose and intention in life (Meleis, 2007; Meleis, et al., 2000). The associated feeling of being well-off and the enhanced connection with others gauge a healthy transition. There has been a favorable adjustment to an alarming event, where one has been able to restore and improve their previous state (Meleis, et al., 2000). Participants in this study spoke about sharing their experiences, being more compassionate and being better off than others. These actions have been articulated with the Grief to Personal Growth Theory, (Hogan & Schmidt, 2002) where one has progressed through the process of grief and loss to achieve a personal growth, where a there was a different worldview.

Within this phase of the process, participants gave to others freely and derived a mutual benefit from those good deeds. Individuals in this study described a personal responsibility to help others. They told of *telling their story*, so that others could profit from their experience. Ekwall, Ternstedt, and Sorbe (2007) described the accountability for others, with women who were fighting ovarian cancer. However, this obligation was in the context of responsibility for their immediate family and loved ones. The findings in this study go beyond that of the personal obligation that one has in close relationships to that of a social duty. This charge was to help others in society gain benefit from their experience.

In the concluding phase of this process, one has incorporated the diagnosis into their life and is able to continue on and live their life.

Living day by day

The final, conceptual category of this basic social process was ***living day by day***. The individuals who participated in this study described the concluding phase of this process as the place where one reaches a positive end. This was a time of stability and poise. Individuals had

incorporated the disease and illness into their life. They continued to live their life, irrespective of limitations. This finding relates directly with the major theoretical work on the concepts of transition and uncertainty. In a transition process, there is a personal change that has taken place over time. The end result of that process is stability (Marineau, 2005; Meleis, et al., 2000). In the theoretical work on the concept of uncertainty, Mishel (1990) contended that uncertainty in illness is a source of instability that shifts a person from an original position toward a new state. The individual undergoes a change, where the initial confusion and disorganization caused by the event is replaced with the acceptance of uncertainty as a part of reality.

The conceptual properties of this category were *being composed* and *steadiness*. These findings directly relate to the previous work on coping (Lazarus, 1991; Stanton, Collins, & Sworowski, 2001; Taylor, 1983), transition (Bridges, 1980; Meleis, et al., 2000; Schumacher & Meleis, 1994), and uncertainty (Mishel, 1988; Mishel, 1990). Coping processes are individual actions that are implemented in an attempt to either solve or manage the emotions incurred by a stressor (Lazarus, 1991). These coping strategies include an active positive reframing, seeking social support and information, and problem solving. Taylor (1983) and Stanton, Collins & Sworowski, (2001) contend that when individuals possess these abilities, they can favorably adjust to a disturbing health event. Taylor (1983) defined adjustment as having a reasonable emotional balance, a sound self-image, maintaining close relationships, finding meaning with the event, and maintaining mastery over ones' life. In the research work of Stanton, Collins, and Sworowski (2001), this definition of a healthy adjustment, was enhanced to include the individual having a preserved functional status, a perceived quality of life, and being able to maintain a positive mood with a low negative affect.

All transitions are personal ventures that result in a change over time. This process ends with stability and one being different (Bridges, 1980). The universal property of the concept of transition has been defined as a change over time (Schumacher & Meleis, 1994). In the later theoretical development of the concept of transition, Meleis, et al., (2000), defined a healthy outcome to a transition event, as when one has reached a fluid integrity, is able to maintain a connection with others, and has developed confidence with the situation. Mishel (1990) recognized this individual change in her work on the concept of uncertainty. She identified this change as the new state that the individual has shifted to where one has accepted uncertainty as a part of reality. In this new state, the emphasis is on a different and more varied life perspective. Both theorists would contend that when one has the capability to assimilate uncertainty and the transition event into their life, that there is the prospect for less individual stress and a healthy outcome (Meleis, et al., 2000; Mishel, 1988; Mishel, 1990).

Unique Findings

The basic social process of how individuals live with the diagnosis of cirrhosis that emerged from this study offers new insight and understanding of the personal difficulty one undergoes with the diagnosis of cirrhosis. It is a linear process that begins with the arresting emotional reaction of being told that one has a diagnosis that for most will be life limiting. This is followed by an intense and focused period where the individual comes to terms with the event. One emerges from this time with the energy to move forward. This momentum is sustained by the individual being able to engage higher level coping skills, employ the support of others and maintain significant personal relationships. These behaviors promote a healthy end where the individual can incorporate the event into their life. They are then able to resume living, enjoy

normal routines, while simultaneously maintaining a balanced emotional stance with a reasonable and practical future outlook.

The product of this research work closely aligns with the Grief to Personal Growth Theory (Hogan, Greenfield, & Schmidt, 2001). The participants in this study describe sadness and fear with diagnosis, follow by a period of isolation. They underwent a period of working it through, reached a turning point to where they were able to evade negative emotions, engage with others, look forward to life events, and live their days with an outlook that was more promising. These findings parallel the Grief to Personal Growth Model, where individuals who have experienced grief with a severe life loss, underwent a process of bereavement that included not only the loss of a loved one, but the passing of a former world. They entered a private, isolated, and pensive time after experiencing the loss of their loved one. Within this time, there was a turn, where the individual could control negative thoughts, reach out to others, restructure meaning and a self-identity, and speak openly about their feelings. These behaviors are the outcome of personal growth. A unique finding in this study, with the diagnosis of cirrhosis being linked to the Grief to Personal Growth Theory, is that individuals appear to go through the grief process with the anticipation of loss versus experiencing the full forfeiture of health.

Another distinct finding of this study, was that individuals specifically *worried about getting liver cancer*, during the early phases of hearing that they have the diagnosis of cirrhosis. This specific finding has not been previously documented. Individuals were intensely aware of this potential consequence with having the diagnosis of cirrhosis. Participants in this study relied on values imparted by family. An explicit finding in this study was that it was very basic and clear-cut expressions that had powerful and long-lasting influence. Participants in this study

spoke of the personal strength they drew from their religious beliefs. Although this finding is not new, an added dimension found in this study, was that individuals were able to abandon some worry and concern because of these beliefs. The conceptual property of *not being in control* is an added dimension in this study and enhances the defining characteristics of *accepting it*.

Participants in this study described going further than a present acceptance. They recognized and acquiesced to the imminent physiologic decline that will happen over time with cirrhosis. This added dimension has not been previously documented in the literature related to the diagnosis of cirrhosis. Individuals perceived that personal behaviors of *well-being* and *determination* would forestall further decline in liver function. This attribute has not been described previously in the literature.

Study Strengths

The strength of the research presented in this study is first, that it was developed from the stories of those who have lived the experience. This human actuality, of living with the diagnosis of cirrhosis, was examined and evaluated utilizing a grounded theory approach, where this phenomenon was differentiated by those who have encountered this reality. The results of this study have contributed to an improved understanding of this occurrence. Secondly, the model takes into account the entire process of how individuals incorporate the diagnosis of cirrhosis and that illness course into their life. The basic social process of how one lives with the diagnosis of cirrhosis is a linear process. It begins with the individual hearing that they have cirrhosis and the initial reaction to this diagnosis. The process follows with a private time when one comes to terms with this event and is able to begin to incorporate this disease and illness into their life. The final phase of this process is a period of stability, control, and hopefulness. During this entire

process, there was always a persistent worry and strain about the future decline in liver function and the outcomes that are associated with those circumstances. The basic social process that emerged from this study had not been previously described or detailed. The result of this study draws attention to a process, where individuals encounter a very troubled and personal phase, followed by a period where they begin to deal with it, and work it through. This is followed by a time of renewed energy, where they can move forward, re-engage in satisfying life events and live their life with a more promising perspective. When those providing care to these individuals, have this awareness, they will be in a different position to appreciate this experience.

The final strength of this study is that it provides knowledge for health care providers to have more complete responses and interventions for those who hold this diagnosis. This study details with specific language, the reaction to a negative health event, private suffering, and personal resolve. The conceptual categories that emerged from this research have given first hand and fresh words to the experience of those who have been given a difficult diagnosis with a subsequent demanding chronic illness experience. When language can augment a link with that which is not empirical, our understanding of another's experience becomes more genuine (Rogers & Knafl, 2000). It is this deeper perspective and mindfulness that abets those caring for these individuals to do more for them.

Study Limitations

A limitation of this study is research is that the study was conducted at a tertiary care facility, with department staff being highly trained and experienced in the care of those with advanced liver disease. This professional acumen could affect a positive end, with this staff being acutely aware of the end result of this diagnosis and already currently sensitive to this population

with advanced liver disease. Mishel (1988) identified this as credible authority and considered this a key determinant in the prevention of uncertainty in illness. Those individuals, who remain under the care of their primary care or local physician, may draw less benefit from that relationship and this may have an opposing effect on a healthy outcome. This population was not captured in this study and could contribute an enhanced perspective in future study. A second limitation to this study, is that those individuals who became lost to follow up, either early in diagnosis or during the illness course, were not captured. These individuals may have non-existent inter and intra personal resources, which would make the implementation of higher level coping processes and a stable end point, less plausible (Lazarus, 1991; Meleis, et al., 2001, Mishel, 1988).

The investigator of this study has had an extensive clinical background with patients who have liver disease. The intense professional involvement with this population over the years may have contributed to bias in the interpretation of results. A final limitation of this study could be perceived with the interview process. In order to maintain consistency, all interviews were done as phone interviews. With this interview process, the researcher does not have the ability to assess non-verbal communication, leaving this form of communication not evaluated or considered.

The following section will address the implications of this research work for nursing practice, research, education, and administration.

Implications for Nursing Practice

The basic social process that is presented from this study directs the attention of nursing to the process that individuals undergo to live with the diagnosis of cirrhosis. Within this process

there are precarious and unstable periods for the individual where the attention of nursing care and therapeutics can be directed. These critical points include the initial period following the diagnosis, when one is in a troubled and solitary place. To move forward from this place, individuals need to rely on personal fortitude, significant life relationships and the support of those providing care to them. Each of these influencing factors are points where the care and attention of nursing can structure better for the individual (Cody, 2006; Corbin, 1993).

This theory contributes to the understanding of the human response to a difficult diagnosis, which is a central tenet in the definition of nursing (ANA, 2003). Imparting the findings of this study would contribute to a thoughtful nursing approach to impact the human experience of living with chronic disease. The nursing actions that could be explored with students or novice practitioners, would include the assumption of responsibility by the nurse when the individual is not able to shoulder that charge, manipulating the situation to facilitate a healthier outcome and assisting the individual in advancing toward some goals (George, 1980). Additional application of the theory would be warranted with individuals who have been given any other chronic disease diagnosis that entails an illness course that has a negative trajectory, an uncertain time line of physiological decline and suffering which is embodied in the loss of physical stamina along with one's personal ambitions.

Other points of the model that direct the attention of nursing is the influence of others and when this support is absent. Nursing assessment of this condition is critical. When this assessment of support is determined to be available to the individual, care can be planned to capitalize on this asset. When this resource is assessed as being absent for the individual, care can be planned to intervene with professional support that can utilize the expertise of multi-

disciplinary team members. These are individuals who may benefit from outreach programs, such as support groups. Another option, may be to offer those with minimal social support, the opportunity to interact with health care professionals electronically, as in a “chat room” forum.

The personal attributes that one has are another influence on a healthy outcome and warrant a nursing assessment. Those that are less optimistic by nature would benefit from the higher-level nursing interventions of teaching and counseling and possibly from the assistance of other team members that could provide additional psycho-social support. A final area that is important for nursing practice is the positive impact of health care provider’s care, and the significance that this has for an individual to reach a stable endpoint. The intervention of nursing care has a decisive role in this end and this outcome could be evaluated in this study, by an individual’s engagement with others, participation in enjoyable life events, and demonstrating low negative affect.

Implications for Nursing Research

Additional study of the theory presented in this paper is needed. The basic social process of how individuals live with the diagnosis of cirrhosis is linear. Study is warranted at the beginning, middle, and end point of this process. It would be expected that there would be reciprocal measures of stress and uncertainty with the individual being able to incorporate this disease and illness experience into their life. Each of these time points would warrant different attention from nursing, with more care and attention being needed at the beginning and middle phases of the process. This theory could be tested as a grief process. Evidence provided from this measure could provide clinicians with more precise times within the process to target assessment and care. Further work is needed to operationalize the concepts that emerged from this study in

order to develop a measurement tool to test and determine differences when specific nursing interventions are applied in a study group.

Implications for Nursing Education

The basic social process that emerged from this study describes the process that one undergoes to live with the diagnosis of cirrhosis. This process involves being able to effectively cope with a difficult situation, the individual undergoing a change over time, and the importance of having the support of others in one's life. The theory that was developed from this research would enhance the ability of nursing faculty to facilitate critical thinking by teaching the process that was articulated in this study that describes a complex event. This focus would contribute to a student's ability to develop the higher level cognitive skills of analysis, inference, interpretation and evaluation (Billings & Halstead, 2009). Those teaching efforts would include emphasizing a comprehensive nursing assessment that includes all facets within the individual's life that influence a response and meaning. This education should also include teaching the skill set that is needed to evaluate personal coping skills, an awareness of the change and difference that the individual is undergoing, and the times within this process that they may be in a very troubled place. At each of these points, the individual would benefit from dedicated nursing care.

Implications for Nursing Administration

The theory that was developed from this research process has application for nursing administration. It is the direct responsibility of nursing leaders to provide resources for nursing care, assess where improvements can be made, and to better the care delivered to the public (Storch, Rodney, & Starzomski, 2004). A finding in this study, that supports other theoretical work, is the benefit individuals gain from provider care (Meleis, et al., 2000; Mishel, 1988).

This care diminishes uncertainty and supports one to reach a stable endpoint. The care for this population, who are under-going a demanding health-illness transition, would include the comprehensive preventive, promotive, and intervening nursing therapeutic interventions of teaching, counseling and planning (Corbin & Strauss, 1991; Meleis, et al., 2000). This skill set is acquired through both clinical experience and education. Staffing considerations for the care of this patient population should include the ability and expertise of the Advanced Practice Nurse, in the care of this patient population in the discharge process from acute care when there has been a new diagnosis of cirrhosis, the outpatient setting after diagnosis, and in the ongoing clinical care of this population. These are times, that the theory developed from this research, points to these individuals needing more nursing care, which includes a comprehensive and ongoing assessment, care strategies to meet those identified needs, and an evaluation of goal achievement.

Conclusion

The basic social process of how individuals live with the diagnosis of cirrhosis had not been previously investigated. The theory that emerged from this study conceptualizes that process and provides an explanation and prediction of behavior. This insight and understanding enables providers of care to have added capability to influence the situation. Additionally, the theory generated from this grounded theory study provides direction for further research. It is with the continued study of complex concepts, such as chronic illness and difficult health-illness transitions, that professional nursing knowledge and wisdom is realized.

APPENDIX A
LETTERS OF SUPPORT FROM PHYSICIANS



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DEPARTMENT OF MEDICINE

Section of Gastroenterology • Center for Liver Diseases

5841 South Maryland Avenue, MC 7120, Chicago, Illinois 60637
 Phone 773-702-2394 • Fax 773-834-1288

Helen S. Te, M.D., A.G.A.F.
 Gautham Reddy, M.D.
 Nancy Reau, M.D.
 Andrew Aronsohn, M.D.

July 7, 2015

To: IRB UCMC
 RE: Mary Tiberg, MSN.
 Letter of support

I am delighted to offer this letter with my strongest possible support for Mary Tiberg's proposed PhD dissertation research study "The diagnosis of cirrhosis: A transition point in nursing care." By way of introduction, I am a hepatologist at The University of Chicago and I currently serve as the Program Director for the Gastroenterology Fellowship as well as the Director of Quality Assurance for the Section of Gastroenterology.

I have known Ms. Tiberg since 2005 when she was recruited from Rush University because of her extensive experience with complicated liver patients. I have found her to be a very skilled healthcare provider but I have been even more impressed with her dedication to the overall well-being of her patients. We have a very large population of cirrhotic patients leading to a variable and difficult to predict clinical course that generally leads to death. We have long observed this diagnosis as psychologically difficult for patients to endure but we have minimal data quantifying the social process these patients go through with regards to the health-illness transition. It is my sincerest hope this research will give us insights to help patients better cope with diagnosis of cirrhosis earlier in their disease course and allow us to help them live more meaningful lives.

Health transition in patients with newly diagnosed cirrhosis is challenging clinical problem that is an unmet need in terms of our understanding. I am fully supportive of Ms. Tiberg's research plan and I will certainly assist with patient recruitment and is any other way needed.

Please feel free to contact me with any questions or concerns.

Sincerely,

Gautham Reddy, M.D.
 Associate Professor of Medicine
 Program Director, Fellowships in Gastroenterology
 University of Chicago Medicine



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Helen S. Te, M.D., FAASLD, FAST, AGAF
Gautham Reddy, M.D.
Nancy Reau, M.D, FAASLD.
Andrew Aronsohn, M.D.

July 5, 2015

Institutional Review Board
University of Chicago Medicine

Re: The diagnosis of cirrhosis: A transition point in nursing care
Applicant's name: Mary Tiberg, MSN
Principal Investigator: Andrew Aronsohn, MD

Dear Sir or Madam:

I am writing in support of Mary Tiberg's research protocol, The diagnosis of cirrhosis: A transition point in nursing care, which seeks to study the various experiences of patients who have been diagnosed with cirrhosis as they live with their chronic disease. She plans to interview about 25 patients from the practices of three hepatologists here at the University of Chicago Medicine, including from my own practice. She hopes to collect adequate data to conceptualize the experiences of these patients and develop a theory on the basic social process experienced by a patient following the diagnosis of cirrhosis.

Ms. Tiberg has been a highly valued and essential member of our Clinical Hepatology team. In her role as a Nurse Associate, she has provided crucial nursing support for the clinician and the patient whose care she is involved in. She has developed an expertise in her field and has built strong rapport with her patients. I am fully supportive of her intent to enroll patients from my clinical practice into her study, as I am confident that she will be able to engage my patients to provide her the information that she is seeking, and that she will treat her study subjects with respect and dignity. Her research question addresses an important aspect of cirrhosis that is often overlooked, as the main focus of the medical team is often the treatment of clinical symptoms and prevention and management of medical complications in this population.

If I can provide additional information, please let me know.

Sincerely,



Helen S. Te, MD, FAASLD, FAST, AGAF
Associate Professor of Medicine
Medical Director, Adult Liver Transplantation
University of Chicago Medicine

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Helen S. Te, M.D., A.G.A.F.
Gautham Reddy, M.D.
Nancy Reau, M.D.
Andrew Aronsohn, M.D.

July 8, 2015

Institutional Review Board
University of Chicago Medicine
Re: The diagnosis of cirrhosis: A transition point in nursing care
Applicant Name: Mary Tiberg, MSN

To whom it may concern:

It is with great pleasure that I write in support of Ms. Mary Tiberg regarding her research protocol entitled "The diagnosis of cirrhosis: A transition point in nursing care." I will be serving as the principal investigator of this study and Ms. Tiberg will be the co-principal investigator. As a transplant hepatologist at the University of Chicago with a busy clinical practice, I feel qualified to take on the role of principal investigator for this study as I frequently care for patients with chronic liver disease and am familiar with the research methods that will be utilized. This area of investigation is not only novel in the field of hepatology, it aims to answer an important clinical question that will have a direct positive impact on patient care.

I have worked closely with Ms. Tiberg since I began as faculty member at the University of Chicago in 2010. Ms. Tiberg has been caring for patients with liver disease for many years at Rush University Medical Center and was recruited to the University of Chicago based on her extensive fund of knowledge, superb nursing skills and unique ability to connect with and comfort patients. I have had the privilege of sharing patient care responsibilities with Ms. Tiberg over the years and her deep concern for her patients not only results in superb clinical outcomes, but also consistently creates a provider patient relationship that I find inspirational. Ms. Tiberg is the type of provider that I would refer a friend or family member to see and I feel fortunate to work with someone of her caliber on a daily basis. Based on Ms. Tiberg's depth of knowledge and character, I have no doubt she will be successful in finding answers to the important research question she has proposed.

As principal investigator, I attest that this study will adhere to all IRB standards and principles of research. I will ensure that all principles and procedures are followed in accordance to the research protocol. In addition, I will be readily available during the entire study period to assist or offer guidance when needed.

Ms. Tiberg will be addressing an important research question and I enthusiastically support her in this endeavor. Please do not hesitate to call me with any questions.

Sincerely,



Andrew Aronsohn, MD
Assistant Professor of Medicine
Center for Liver Diseases
University of Chicago Medicine

APPENDIX B
LETTER FOR HEPATOLOGISTS

Dear Dr. _____ (name),

I am currently seeking individuals with the diagnosis of cirrhosis to participate in a research study, being conducted as part of the requirements for the PhD in Nursing degree at Loyola University Chicago. The purpose of this study is to gain a deeper understanding of the process and change over time that individuals undergo when a diagnosis of cirrhosis is made.

English speaking participants that have a diagnosis of cirrhosis with a MELD score of < 20 are being recruited. Individuals who have developed encephalopathy or in the pre-transplant evaluation along with those individuals who continue to struggle with illicit drug and alcohol dependence would not be candidates recruited for this study.

Information will be gathered from individual interviews, which will be conducted in either the outpatient facility where they have an office visit, or in a phone interview if that is more convenient for them. The time for the interview will be at their convenience. Interviews are expected to take about an hour. Participants will receive parking validation if the interview is conducted either before or after an outpatient visit, and they will also be given \$25.00 gift card as a token of appreciation.

If any of your patients are interested in participating in this study, or if there are any further questions, please contact me at 773-834-3584 (office) or mtiberg@medicine.bsd.uchicago.edu. A flyer outlining the details of this study is attached.

Sincerely,

Mary Tiberg, MSN, RN

PhD in Nursing Candidate, Loyola University Chicago

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

Research Study Title:

The diagnosis of cirrhosis:

A transition point in nursing care.

Purpose: The purpose of this research study is to investigate the experience of those individuals who are living with a diagnosis of cirrhosis.

Eligibility Criteria: Diagnosis of cirrhosis; over the age of 18

Study Description: Data will be collected through a face-to-face or telephone interview. The time and place of the interview will be scheduled at your convenience.

Enrollment and Contact Information:

Mary Tiberg, RN, MSN; PhD in Nursing Candidate at Loyola University Chicago

Phone: 773-834-3584

Email: mtiberg@medicind.bsd.uchicago.edu

As a thank you for your participation, a \$25.00 Visa gift card will be provided at the end of the interview. If the interview is conducted at the University of Chicago Medical Center, your parking will also be validated.

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

APPENDIX C
ORAL SCRIPT FOR STUDY PROTOCOL

The Diagnosis of Cirrhosis: A transition point in Nursing Care
IRB 15-1052

1. Let me introduce myself. I am Mary Tiberg and I am currently a doctoral student in nursing at Loyola University in Chicago. My research involves a specific point in liver disease, specifically when one is diagnosed with cirrhosis.
2. I received your contact information from your hepatologist, (Dr Te or Dr Reddy). He/She thought that you may be interested in participating in the study that I am conducting.
3. I am calling today to ask if you are interested in participating in this study. This study involves answering some questions about your diagnosis of liver disease and cirrhosis.
4. This interview will take about an hour of your time.
5. If the patient is interested in participating, I will move on to the oral consent. I will verbally review the oral consent with the participant and obtain verbal consent.
6. It will be reinforced before beginning the interview that the participant may choose to not answer any question and can stop the interview at any time.
7. I will then begin the interview by asking general introductory questions which will include
 - a. Age/sex
 - b. Marital status/lifetime partner
 - c. Number of children
 - d. Years of education
 - e. Occupation
8. I will then move on to the specific questions for this study which include:
 - a. Please tell me about the symptoms that you had that resulted in your finding out that you had liver disease.
 - b. How long were you diagnosed with your initial disease before you were told that you had cirrhosis?
 - c. Please tell me about that day when you were told that you had cirrhosis.
 - d. Tell me about the time since that diagnosis. What has that been like for you?
 - e. How has this diagnosis affected your life?
 - f. Tell me about living with your disease now.
 - g. What helps you to live with this diagnosis?
 - h. What has helped you cope with this diagnosis?
 - i. What things have made it harder to cope with this diagnosis?
 - j. Is there anything you would like to tell me that I didn't ask about?
9. Thank you for your time. You will receive a \$25.00 Visa gift card, which I will be mailing to your home address. I have that address as..... Is this correct?
10. I will also be enclosing a copy of the verbal consent, which has contact information, if you need it in the future for any reason.

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

APPENDIX D
IRB APPROVALS

Tiberg, Mary [UCH]

From: Schmidt, Lee <Lschm3@luc.edu>
Sent: Tuesday, September 15, 2015 3:44 PM
To: Tiberg, Mary [UCH]
Subject: FW: IRB Research Project 208027

Dear Mary,
 Congratulations! You have approval from Loyola and can begin your study.
 Dr. Schmidt

Lee A. Schmidt, RN, PhD
 Associate Professor
 Senior Associate Dean for Academic Affairs
 Associate Dean for Undergraduate Programs
 Marcella Niehoff School of Nursing
 (773) 508-3466

From: IRBportalprocess@luc.edu [mailto:IRBportalprocess@luc.edu]
Sent: Tuesday, September 15, 2015 3:06 PM
To: Schmidt, Lee <Lschm3@luc.edu>
Cc: Schmidt, Lee <Lschm3@luc.edu>; Kennedy, Richard <rkennedy@luc.edu>
Subject: IRB Research Project 208027

NOTICE OF FULL APPROVAL OF A RESEARCH PROJECT

Date: 09/15/2015

Investigator: Schmidt, Lee A
 LU Number: 208027
 TITLE: The Diagnosis of Cirrhosis: A Transition Point in Nursing Care
 ITEMS SUBMITTED FOR REVIEW:

- 09/12/2015 University of Chicago IRB submission
- 09/12/2015 University of Chicago IRB approved flyer
- 09/12/2015 University of Chicago IRB approved script
- 09/12/2015 University of Chicago IRB Approval

Dear Investigator,

The above-referenced research project was given Full Approval by the
 Institutional Review Board on 09/15/2015.
 YOUR PROJECT MAY NOW BEGIN.

AURA

THE UNIVERSITY OF
CHICAGO

BSD IRB

The University of Chicago Biological Sciences Division/University of Chicago
Medical Center
5751 S. Woodlawn Ave., 2nd floor, Chicago, IL 60637
FWA00005565

Notification of Expedited Approval

Date of Letter: 8/31/2015

Protocol [IRB15-1052](#)

Number/Submission

Link:

Type of Submission: New Study

Status: **Approved**

Principal Investigator: Andrew Aronsohn

Protocol Title:

The Diagnosis of Cirrhosis: A transition point in nursing care

Risk Level: Minimal Risk

Consent Type: Waiver of Documentation of Consent

Authorization Type: Requesting waiver/alteration of authorization, including oral consent

Vulnerable Populations: None

Funding:

Internally Funded

Protocol Version: Study proposal

Stamped Documents: consent IRB changes.docx.pdf

Oral script for study protocol.docx.pdf
Recruitment tools.pdf

Approval Date: 8/31/2015

The above-referenced study was approved by the IRB. The expiration date of this study is 8/30/2016.

Stamped approved documents associated with this study can be found in the study workspace, by following the Submission Link above.

If you need assistance, please contact the IRB from the submission workspace by clicking the "Send Email to IRB Team" activity.

Please refer to your IRB's current policy and procedure manual available at:
<http://humansubjects.uchicago.edu/>.

APPENDIX E

ORAL CONSENT SCRIPT FOR PARTICIPATION IN RESEARCH

IRB NUMBER: 15-1052

**University of Chicago Medical Center
5841 South Maryland Avenue
Chicago, Illinois 60637**

PROJECT TITLE: The diagnosis of cirrhosis: A transition point in nursing care.

You are being asked to take part in a research project. It is important that you read and understand the principles that apply to all individuals who agree to participate in the research project described below:

1. Taking part in the research is entirely voluntary
2. You will not benefit from taking part in the research, but knowledge obtained may help others.
3. You may withdraw from the study at any time without anyone objecting and without penalty or loss of any benefits to which you are otherwise entitled.

You are being asked to participate in this research study because you have been diagnosed with cirrhosis of the liver and because you are receiving treatment for your condition at the University of Chicago Medical Center.

This research study is being conducted by Mary Tiberg as part of her doctoral degree program at Loyola University. The Principal Investigator for this study at the University of Chicago is Dr. Andrew Aronsohn from the Department of Gastroenterology.

The purpose of this study is to investigate the experience of those individuals who are living with a diagnosis of cirrhosis. This information will be used to develop a deeper understanding of that experience. Approximately 20 individuals will participate in this research.

If you agree to be in this study, you will be asked to participate in an interview that will be approximately one hour in length. The interview can be conducted either in-person at the University of Chicago or by telephone, if you prefer. During the interview you will be asked about what it was like for you when the diagnosis of cirrhosis was made and what it has been like for you since that day. The interview will be tape recorded in order to capture your responses and review them at a later time. These tapes will only be listened to and transcribed by Mary Tiberg, the co-investigator for this study and doctoral candidate at Loyola University Chicago. The tape will be destroyed one year after the study completion.

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

The information obtained during your interview will be combined with information obtained in the other interviews conducted in the course of the study.

RISKS/DISCOMFORTS: There is no foreseeable risk with this study. You may become experience some sadness as you share some of your memories and experience with having the diagnosis of cirrhosis. You do not have to answer any questions that you do not want to, and if at any time during the interview, the questions become too difficult, you may choose to not continue with the interview or study participation.

BENEFITS: There is no direct benefit to you for your participation. Information that is gained will be useful in getting a deeper understanding of the experience of receiving and living with a diagnosis of cirrhosis.

ALTERNATIVES: You do not have to participate in this research project. Your decision about participation will not affect your care at the University of Chicago Medical Center.

FINANCIAL INFORMATION: Parking will be validated, if the interview is done in the outpatient clinic at the University of Chicago. In appreciation of your time, you will be given a \$25.00 VISA card at the completion of the interview.

CONFIDENTIALITY: All of your information will be kept confidential. The audio tapes will be stored in a locked cabinet to which only Mary Tiberg and, Dr. Lee Schmidt, her Dissertation Committee Chair at Loyola, and Dr. Aronsohn will have access. You will not be identified individually in any reports. Information will not use identifiers that in any way could be linked to you. The audio tapes will be destroyed one year after study completion. Your records may be reviewed by federal agencies whose responsibility is to protect human subjects in research including the Food and Drug Administration (FDA) and Office of Human Research Protections (OHRP). In addition, representatives of the University of Chicago, including the Institutional Review Board, a committee that oversees the research at the University of Chicago, may also view the records of the research. If your research record is reviewed by any of these groups, they may also need to review your entire medical record. During your participation in this study, you will have access to your medical record. Mary Tiberg and Dr. Aronsohn are not required to release to you research information that is not part of your medical record.

The results of this study will be submitted for publication and may be presented at professional conferences. Quotations from selected interviews may be used as examples in publications or presentations, but no identifying information will be presented with those quotations.

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

If you have questions about your participation in this research study, you may contact Andrew Aronsohn, M.D. at aaronsohn@medicine.bsd.uchicago.edu. Mary Tiberg and Dr. Lee Schmidt are the co-investigators for this study. Mary Tiberg can be contacted at mtiberg@medicine.bsd.uchicago.edu, or 773-834-3584 and Dr. Lee Schmidt can be contacted at lschm@luc.edu, or 773-508-3466.

Study ID:IRB15-1052 Date Approved: 8/31/2015 Expiration Date: 8/30/2016

APPENDIX F
SAMPLE CHARACTERISTICS

Sample Characteristics

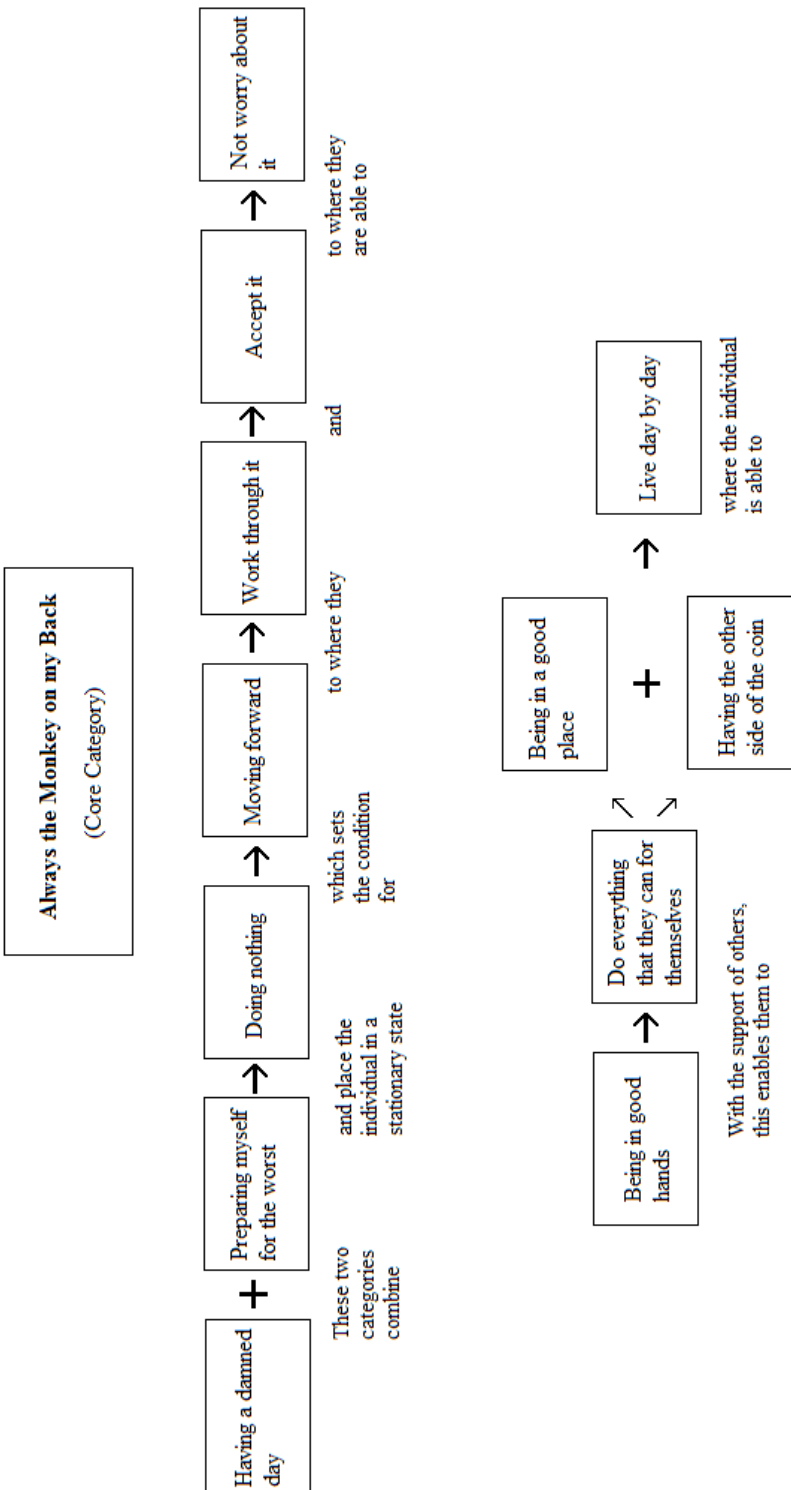
Age range of participants	50-76 years old
Time with diagnosis	2 months – 3 years
Educational level	9 th grade – PhD
Significant relationships	7 (41%) married, 4 (23%) single, 2 (12%) were widowed, 1 (.05%) had a lifetime partner, and 3 (18%) were divorced

Cause of Cirrhosis

Hepatitis C	13 (76%)
Alcohol	2 (12%)
Autoimmune disorder	1 (0.05%)
Cryptogenic	1(0.05%)

APPENDIX G

DIAGRAM OF THEORETICAL FRAMEWORK: LIVING WITH THE
DIAGNOSIS OF CIRRHOSIS



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VITA

During the past 15 years of her career, Mary Tiberg has worked in both the administrative and clinical aspects of chronic disease. This experience has included a broad range of program initiatives and clinical research activities. These chronic disease program initiatives included the design, implementation, and sustainment of three disease management programs (Heart Failure program, Diabetes health management, and a Stroke Unit). Her research experience has included a broad range of activities, including a NIH sponsored clinical trial, participation in large RCT for drug investigation, and specific principle investigator sponsored trials. Currently, her work is in the coordination and management of outpatient hepatology patients. These responsibilities involve assuring patient access to care, adherence, and effectiveness of interventions.

During her career, Tiberg has been recognized for professional contributions and has received awards including the Meritorious Civilian Service Medal from the Department of the Navy; Certificate of Commendation from the Commanding Officer of the Naval Hospital, Okinawa, Japan; Nurse of the Year award, University of Chicago; and the GI Fellowship Staff Support award, University of Chicago.

Tiberg's research interest is with those individuals who have end stage liver disease. This research work has been directed at the time points in care where the directed actions of nursing can improve care and overall quality of life for these individuals. Her initial research work was with those individuals who are diagnosed with cirrhosis. This work will be the foundation for future research, where the implementation of health care strategies can be tested and evaluated.

