MOTHERS WITH CHRONIC ILLNESS AND THEIR SPOUSE/PARTNER: UNCERTAINTY, FAMILY HARDINESS, AND PSYCHOLOGICAL WELLBEING

by

Margaret Cordell Noreuil

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

(Nursing)

at the

UNIVERSITY OF WISCONSIN-MADISON

2002

Dedicated to my family
Scott, Josh and Brittany Noreuil
Joe and Peggy Cordell
Joyce, Joe Sr., Joe Jr., Sarah and David Oxencis
Susan, Nick, Andy, Ashley and Amy Noreuil

Table of Contents

List of Tables

List of Figures

Page

marriage. Love and thanks to my son, Josh, for reminding me of the importance of not giving up, but pushing to cross the finish line no matter how high the hill or how long the road. I admire your determination to go the extra mile(s). To my daughter, Brittany, love and thanks for making me stop and question what is really important in life- you are wise beyond your years. My parents, Joe and Peggy Cordell, deserve special love and thanks for teaching me that any job worth doing is only worth doing well and always encouraging me to believe that I was capable of doing the job well. Thanks also goes to my two best friends, my sisters Joyce and Susan, and their families for providing all of us with enough fun times to far outweigh the stressful times all families experience.

Finally, thanks to all the families that participated in the study. Without their help this research would not have been possible.

This study was funded by two scholarships from the School of Nursing at the University of Wisconsin-Madison (Helen Denne Schulte funding and the Charles Eckburg Scholarship) and from a scholarship from the Nurses Foundation of the Wisconsin Nurses Association (WNA).

Abstract

MOTHERS WITH CHRONIC ILLNESS AND THEIR SPOUSE/PARTNER: UNCERTAINTY, FAMILY HARDINESS AND PSYCHOLOGICAL WELL BEING

Margaret Cordell Noreuil

Under the supervision of Professor Marilyn McCubbin

At the University of Wisconsin-Madison

Mothers with chronic illness are expected not only to manage their chronic illness but also to continue to manage both family and work roles and obligations. More women today simultaneously occupy three major social roles: parent, spouse/partner, and wage earner. The ability to manage all three roles, and do them well, is difficult for healthy mothers; for a mother living with chronic illness, it may be impossible.

The purposes of this study were to: (1) describe levels of uncertainty, family hardiness, and psychological wellbeing in both mothers with a chronic illness and their spouse/partner; (2) test for direct and moderating effects of uncertainty and family hardiness on psychological wellbeing in mothers and their spouse/partner; (3) examine congruency between mothers' and spouse/partners' uncertainty and family hardiness and the relationship to their psychological wellbeing; and (4) examine mothers and spouse/partners responses to open ended questions asking how they deal with the uncertainty of chronic illness and what advice they have for other families living with a mother with chronic illness.

Family Systems Theory (Whitechurch & Constantine, 1993) and The Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996) are the theoretical frameworks for this study.

This study is a cross sectional correlational study. Families who have a mother living with chronic illness and at least one child under the age of 18 living at home were eligible for participation. Sixty mothers and 30 spouse/partners participated in the study.

For mothers and spouse/partners, family hardiness was a significant predictor of psychological wellbeing. No moderating effects were found for uncertainty and family hardiness on the psychological wellbeing of mothers and their spouse/partner. Mothers' family hardiness was positively correlated with spouse/partners' wellbeing. Mothers' uncertainty was positively correlated with spouse/partners uncertainty. For the spouse/partner, neither family hardiness nor uncertainty were associated with mother's psychological wellbeing.

Four general themes were identified from mothers and spouse/partners responses to questions about living with chronic illness: (1) *Education,* which included educating others about the illness, including the impact of the illness on the family, was important to mothers and their spouse/partners; (2) *Seeking support* was important and included asking others for help and seeking support from others; (3) *Creative problem solving,* which included setting priorities and simplifying their lives, was often used by mothers and their spouse/partner to manage life with chronic illness; and (4) *Living for today* was an important way to manage their chronic illness and included living day by day and planning activities at the last minute to manage the unpredictability of chronic illness.

Mothers with chronic illness and their spouse/partner face many challenges in living with chronic illness. It is important for families living with chronic illness to learn to manage their chronic illness in order to live as "normal" a life as possible. Health care services are shrinking and families are given more responsibility to care for family members living with chronic illness. Health care professionals need to empower families, focusing on family strengths and resiliency factors such as family hardiness in an effort to promote the psychological wellbeing of all family members.

Chapter I

Introduction

Statistics indicate that approximately 30% of adults between the ages of 18-44 years of age are living with at least one chronic illness (National Center for Health Statistics, 2001). For adults born since 1950, chronic illness has replaced acute infections as the major cause of death (National Center for Health Statistics, 2001). Many adults, ages 25-44, experience chronic illnesses that are not necessarily life threatening but are debilitating, such as chronic fatigue syndrome and migraine headaches (Armstead, L., Klein, K., & Forehand, R., 1995). The prolonged course of illness and disability from chronic illness results in extended pain and suffering, and decreased quality of life for millions of adults. A large majority of health care dollars in the United States are spent every year on the treatment and/or control of chronic disease. In recent years, advances in technology and treatment within the field of medicine have led to increasing numbers of persons with chronic illness being cared for by family members at home (Armstead et al.). Twenty years ago people with chronic illness often spent extended stays in acute care settings trying to control/treat their chronic illness and its accompanying difficulties. Today people with these same illnesses are expected to manage and treat their chronic illness in a home setting, often with the help of family members.

Research on chronic illness needs to begin with the definition of chronic illness. The National Commission on Chronic Illness, which was founded in 1949, provided one of the earliest formal definitions of chronic illness. This definition included "all impairments or deviations from normal that have one or more of the following characteristics: are permanent; leave residual disability; are caused by nonreversible pathological alteration; require special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care" (Dimond, 1984). More recent definitions have defined chronic illness around several dimensions, one of which is time. Chronic illness is usually differentiated from acute illness by how long it persists. The National Center for Health Statistics considers an illness chronic if it lasts longer than three months (Pollin, 1994).

Lifestyle is another dimension that differentiates acute from chronic illness. An illness that is long term or permanent and interferes with the person's ordinary physical, psychological, or social functioning may be termed chronic (Hymovich & Hagopian, 1992). The definition of chronic illness that will be used for this study is an illness that is gradual in onset, relapsing/episodic in its course, and mild to moderately incapacitating.

Mothers with chronic illness are expected not only to manage their chronic illness but also to continue to manage both family and work roles and obligations. More women today simultaneously occupy three major social roles: parent, spouse/partner, and wage earner. The ability to manage all three of these roles, and do them well, is difficult for healthy mothers; for a mother living with chronic illness, it may be impossible.

Chronic illness is usually accompanied by numerous complications, including pain, activity limitations, sleep disturbance, fatigue, side effects of medications, appetite changes, depression, anxiety, and disability. In addition, dealing with uncertainty tends to be a common experience when living with chronic illness due to the unpredictable and inconsistent onset of symptoms, continual questions about recurrence, and unknown future (Mishel, 1999).

organization (McCubbin, Thompson & McCubbin, 1996). When families are unable to adjust their lives in order to manage the stressor, they must learn new patterns of functioning in order to successfully adapt to living with chronic illness.

Clinicians and researchers recognize the value of looking at the family when assessing the impact of chronic illness. In the past decade there have been an increasing number of studies that have focused primarily on how adults with chronic illness react to their disease, and how parents cope with a child with chronic illness (Donnelly, 1994; Faille & Jones, 1991; Fleury, 1995; Hymovich & Hagopian, 1992; Svavarsdottir, McCubbin & Kane, 2000). There has been less research that has focused on variables that predict individual wellbeing when the mother has a chronic illness (Lewis, Hammond & Woods, 1993; Woods & Lewis, 1995; Thorne, 1990; Wineman, Durand & Steiner, 1994). In addition, the impact of uncertainty and family hardiness for mothers living with chronic illness has not been examined in past research studies.

Rolland's Psychosocial Typology of Chronic Illness (Rolland, 1994) consists of clinically meaningful and useful categories for a wide array of chronic illnesses affecting individuals across the entire life span. Rolland's model of illness describes diseases and disabilities in psychosocial terms and provides a useful guide for both clinical practice and research. The psychosocial typology conceptualizes broad distinctions of chronic illness based on the pattern of 1) onset; 2) course; 3) outcome; 4) type and degree of incapacitation; and 5) degree of uncertainty. These five categories are hypothesized to be the most psychosocially significant for a wide range of illnesses and disabilities. In addition, they were chosen because the type of onset, course of disease, and outcome strongly influence the nature of the developmental tasks associated with each of the time phases of an illness: 1) crisis (prediagnosis and diagnosis); 2) chronic; and 3) terminal. These categories were not designed for traditional medical treatment or prognostic purposes, but for examining the relationship between family or individual dynamics and chronic illness. In this study, drawing on Rolland's (1994) psychosocial typology of chronic illness, chronic illness will be defined as an illness that is gradual in onset, relapsing/episodic in its course, and mild to moderately incapacitating.

Family Systems Theory (Whitchurch & Constantine, 1993) and the Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) are the theoretical frameworks for this study. Family Systems Theory suggests that the family is a system composed of interacting subsystems and that changes in one part of the family are followed by compensatory changes in other parts of the family. In this study, the assumption is that the event of chronic illness affects not only the individual diagnosed with chronic illness, but also the other members of the family and the family as a unit.

The Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) emphasizes family adjustment and adaptation when families experience stressful life situations. In the adjustment phase, families initially use previously established patterns of functioning and may need to make only minor changes in how the family unit operates. When minor changes are not adequate to manage stressors, the family moves into a crisis situation that results in the family making more major changes in order to restore functional stability. In this phase, the adaptation phase, response to a crisis situation is determined by the accumulation of demands that the family experiences, the family's newly established patterns of functioning, the family's resources and social support, the family's appraisal of the situation and the problem solving and coping responses of the family to the total family situation (McCubbin & McCubbin, 1993;

1996). In this study, families are in the adaptation phase as they are trying to adapt to a life with chronic illness.

The purposes of this study were to: (1) describe levels of uncertainty, family hardiness, and psychological wellbeing in both mothers with a chronic illness and their spouse/partner; (2) test for direct and moderating effects of uncertainty and family hardiness on psychological well-being in mothers and their spouse/partner; (3) examine congruency between mothers' and spouse/partners' uncertainty and family hardiness and the relationship to their psychological wellbeing; and (4) examine mothers and spouse/partners responses to open ended questions asking how they deal with the uncertainty of chronic illness and what advice they have for other families living with a mother with chronic illness.

Chapter II

Theoretical Frameworks

Family Systems Theory

General systems theory was developed from the fields of physics and biology by von Bertalanffy (1968). General systems theory (GST) states that a system is composed of a set of interacting elements and that each system is identifiable as distinct but interacting with the environment in which it exists. Family Systems Theory is derived from General Systems Theory. One of the key assumptions of GST is the concept of holism, that is, a system is understood as a whole and cannot be comprehended by examining its individual parts in isolation from each other. Because parts of the system are interdependent, behaviors or changes in one part of the system generally affect other parts of the system. In families, this means events that happen to one member of the family, such as chronic illness, affect other members of the family.

When the family is the defined system, systems theory can be used to understand intrafamily processes such as family functioning, family communication, family conflict, separateness and connectedness among members, cohesion, integration, and adaptation to change (Whitchurch & Constantine, 1993). In addition to the family system, family researchers consider subsystems, which are smaller than the family system. These include the individuals in the family and the various subsystems to which he/she belong (e.g., marital subsystem, parent/child subsystem).

Family Systems Theory also considers systems larger than families, called suprasystems, which include extended family, culture, community, geographic region, and national system (Whitchurch & Constantine, 1993). Family researchers consider family issues from several system levels in order to explore questions in more depth than would be possible with a more linear approach.

There are boundaries as well as hierarchies within the family system and relationships between subsystems, e.g., mother-child, family-community. Families have features designed to maintain stability or homeostasis, although these features may be maladaptive or adaptive. At the same time, the family is considered to change constantly in response to stress from the external environment, and change in one part of the system affects the entire system. Some of these stressors are normal developmental stressors that all families experience but some may be the result of an unexpected event, such as the diagnosis of chronic illness.

Systems theory also can describe and explain changes in the structure of family systems. Families make minor structural changes when faced with certain events without changing the structure of the system (first-order change). It is through second-order change, which is a major, higher level of change, that the system itself is altered. This change is much more dramatic and enduring. It is with second-order change that the system itself is reorganized. In this study, living with chronic illness is considered a second-order change because families must change and reorganize in numerous complex ways in order to adapt to a new level of functioning.

Crisis may occur in the family and the family must learn new roles and rules to deal with the new situation. Mothers play a critical role in the health and wellbeing of families. When mothers are ill it becomes difficult, if not almost impossible, for them to continue in this role. The family system perspective views individual family members as part of a family system. Using this perspective promotes assessment of the effects of illness upon the entire family and the effects of family functioning on the individual with the illness (Wright & Leahy, 2000).

This study will examine the levels of uncertainty, family hardiness, and psychological wellbeing in both mothers with a chronic illness and their spouse/partner and examine the effect of uncertainty and family hardiness (family stress resistance resource) on psychological wellbeing in mothers and their spouse/partner.

The strengths of the family systems framework include the fact that this theory covers a large array of phenomena and views the family within the context of its suprasystems (the larger community in which it is embedded) and its subsystems. In this study, the family is considered within the context of the subsystem of the mother and spouse/partner in the family.

The Resiliency Model of Family Stress, Adjustment and Adaptation

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) (See Figure 1) builds on the work of Reuben Hill (1949, 1958) and his ABCX Model depicting the pre-crisis variables of the stressor (A), resources (B), and the definition of the stressor (C) which predicts whether families will go into a crisis (X). The Double ABCX Model (H.I. McCubbin & Patterson, 1981, 1983a, 1983b) was then developed with a focus on both pre-and post crisis factors that facilitate family adaptation to crisis situations. The Family Adjustment and Adaptation Response Model followed as an extension of the Double ABCX Model with an emphasis on describing the processes involved in the family's efforts to balance demands and resources (Lavee, H.I. McCubbin, & Olson, 1987). Later, the Typology Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1987, 1989) was developed to emphasize the importance of the family's established and newly created patterns of functioning as buffers against family dysfunction, and factors in promoting adaptation and recovery. The

Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993; 1996) is the most current extension of these earlier models and is a theoretical framework that emphasizes the resiliency of families or their ability to recover from stressful events and adversity and what strengths and capabilities influence the process of adaptation. According to this model, response to stressful life events occurs in two phases over time: (1) adjustment phase; and (2) adaptation phase.

ADJUSTMENT PHASE

In the adjustment phase, families initially use previously established patterns of functioning and may need to make only minor changes in how the family unit operates. When faced with a stressor such as chronic illness, successful adjustment is determined by many factors. The stressor interacts with the family's vulnerability, which is shaped by the pileup of family stressors, transitions, and strains occurring in the same time period as the stressor (A) (See Figure 1). Family vulnerability (V) interacts with the family's typology, which is the established patterns of functioning (T). These components interact with the family's resistance resources (B). This, in turn, interacts with the family's appraisal (C) of the stressor. The family appraisal interacts with the family's problem solving and coping strategies (PSC) (McCubbin & McCubbin, 1993). Families may need to make only minor changes in their level of functioning in order to achieve a satisfactory level of adjustment (bonadjustment). If these minor changes do not result in a satisfactory level of adjustment the family experiences a crisis situation, which heralds the onset of the adaptation phase.

ADAPTATION PHASE

Some stressors do not create major problems in families, however, in illness situations, particularly chronic illness, problems are often numerous and complex, demanding more substantial changes in the family system. Families in this situation require new patterns of functioning to restore stability, order, and a sense of coherence. The need to initiate changes in the family's pattern of functioning is considered a crisis and heralds the beginning of the adaptation phase. The level of family adaptation is determined by several interacting components (McCubbin & McCubbin, 1993). The pileup (AA) (See Figure 1) of demands on or in the family system created by the illness, family life-cycle changes, and unresolved strains interacts with the family's level of regenerativity or resiliency (R). Resiliency is determined in part by the newly established patterns of family functioning and retained established patterns of functioning. These components interact with the family's resources (BB), which are supported by family and friends (BB) in the community and by the family's appraisals. A situational appraisal (CC) is formed from the perceived relationship between the family's resources and the demands of the situation. The family appraisal of the crisis situation (CC) interacts with the family's schema appraisal (CCC). This interaction creates a family meaning that is attached to the illness and the changes it produces. The resource and appraisal components then interact with the family's problem-solving and coping repertoire (PSC) to facilitate family adaptation to the crisis (McCubbin & McCubbin, 1993).

Family adaptation is used to describe the outcome of family efforts to bring about a new level of functioning. Bonadaptation involves positive change in the family and positive transactions between the family and the community and its agencies. Some families may not achieve a satisfactory level of adaptation (maladaptation) and as a result, they return to a crisis situation (XX) and then must to find a new ways to adapt.

Adaptation involves the influence of protective factors in facilitating the family's ability and efforts to maintain its integrity, functioning, and fulfill developmental tasks in the face of risk factors (McCubbin, McCubbin, Thompson, Han, & Allen 1997). McCubbin, Thompson, Pirner, and McCubbin (1988) identified family hardiness as one of eleven protective factors that are reflective of resilient families.

Family hardiness refers to the internal strengths and durability of the family unit and is characterized by a sense of control over outcomes of life, a view of change as growth producing, and an active rather than passive orientation in adapting to stressful situations (McCubbin, Thompson, & McCubbin, 1996). Thus, family hardiness has three components: (1) the family's *co-oriented commitment* or working together to manage difficulties; (2) the family's emphasis on viewing hardships as *challenges*; and (3) the family's sense of internal *control* rather than being the victim of circumstance.

Families struggle to achieve a balance and a fit at both the individual-to-family and the family-to-community levels of functioning. In the individual-to-family level, families are trying to achieve a balance between meeting the needs of individual members of the family and the wellbeing of the family as a whole. In families who have a mother with chronic illness, a balance is sought between meeting the needs of the member with chronic illness and the needs of the spouse/partner and any other family members. Families are in the adaptation phase at this point in time, as chronic illness often demands changes in the family's established patterns of functioning and new ways of coping, problem solving and appraisal. In this study, uncertainty is viewed as a stressor (AA), family hardiness as a stress resistance resource (BB), and the outcome, psychological wellbeing, is viewed as the individual to family fit level of adaptation.

Chapter III

Literature Review

Research on mothers in the family has tended to focus on the effects of women's employment on the family and in the allocation of roles based on role theory. The degree to which women adjust to career demands yet maintain traditional sex-role obligations has been documented (Marks & MacDermid, 1996; Parcel & Menaghan, 1994; Stryker, & Statham, 1985; Barnett, 1994; O'Neil & Greenberger, 1994). Role overload, role conflict and role strain are examined and documented in numerous studies of mothers who are not experiencing the added stress of chronic illness. Studies consistently confirm that the routine arrangements of family life are characterized by inequity that consistently disadvantages women despite the women's movement (Dressel and Clark, 1990; Hochschild, 1989; Kahn, 1991).

Since World War II more women have entered the workforce, which has resulted in dual-earner families actually having three jobs: the husband's paid work, the wife's paid work, and the family work, the majority of which is still done by women (Walker, 1990). As more women enter the work force, family expectations regarding the mother's role as well as the father's role have changed. Although more men are assuming more household activities (Spitz, 1988), working women still spend much more time than their husbands in household work. In a study of 234 dual-earner wives, women were employed an average of 38 hours per week outside the home and reported spending approximately 37 hours per week on household chores, compared with their husbands' 20 hours per week spent on household chores along with full-time employment of 40 hours per week (Hawkins, Marshall & Meiners, 1995). The addition of chronic illness only increases the work burden for mothers. Typically, illness arrangements, such as arranging for alternative child care and staying home from work to care for ill family members, revolves around women and women's work as it is women who carry the largest share of the illness burden in the family (Anderson & Elfert, 1989; Kahn, 1991; McGoldrick, 1989).

One of the documented roles of mothers is that of caregiver (Marks, 1998). Mothers act as the main source of comfort and assistance in times of illness, as well as being the primary health care decision maker, educator, and counselor in the family. The importance of the mother as a health care leader in the family becomes most obvious when she is ill and unable to carry out her roles. The mother has been observed to assume the sick role only when it is absolutely necessary, and then only reluctantly (Friedman, 1998). Because the mother's roles are considered critical to optimal family functioning, her illness tends to affect all members of the family. For mothers with chronic illness, this can be a recurring and persistent problem for her and her family.

Psychosocial Typology of Chronic Illness

Rolland (1994) suggests a psychosocial typology of chronic illness, which gives a better way of understanding the impact of chronic illness on the family. Rolland's model of illness describes diseases and disabilities in psychosocial terms and provides a useful guide for both clinical practice and research. This typology of illness consists of clinically meaningful and useful categories for a wide array of chronic illnesses affecting individuals across the entire life span.

Rolland's typology conceptualizes broad distinctions of chronic illness based on the pattern of 1) onset; 2) course; 3) outcome; 4) type and degree of incapacitation; and 5) degree of uncertainty. These five categories are hypothesized to be the most psychosocially significant for a wide range of illnesses and disabilities. They were also chosen because the type of onset, course of disease, and outcome strongly influence the nature of the developmental tasks associated with each of the time phases of an illness: 1) crisis (prediagnosis and diagnosis); 2) chronic; and 3) terminal. The categories were not designed for traditional medical treatment or prognostic purposes, but for examining the relationship between family or individual dynamics and chronic illness.

ONSET: Illnesses can be divided into those that have either an acute or gradual onset. This is not meant to differentiate when the body first begins to experience chronic illness at the cellular level, but to highlight the kinds of symptomatic presentation that people subjectively note (either the person with the disease or by other people). Examples of acute onset include stroke, traumatic brain injury, or meningitis. Examples of gradual onset include chronic lung disease, multiple sclerosis, and Parkinson's disease. The ill person and family will experience different types of stressors depending on the type of onset of the disease. Some individuals and families are better able to cope with rapid change and therefore are a better "match" with a sudden onset type of disease, where others need time to adjust to change and handle a disease with a gradual onset better. However, while the slower the rate of change required to cope with gradual-onset disease allows for a longer period of adjustment, it may generate more anxiety before the diagnosis is made (Rolland, 1994). Mothers often conceal or hide symptoms of chronic illness in an effort to make life appear "normal", a process Robinson (1998) refers to as "normalization". Thus, the onset of chronic illness is often difficult to pinpoint for families and may be much later than the time of onset recognized by the mother.

COURSE: The course of chronic disorders can take three general forms: progressive, constant, or relapsing/episodic. Each gives the family different psychosocial challenges. A progressive disease is one that is continually symptomatic and increases in severity. Examples include Alzheimer disease and rheumatoid arthritis. In a progressive course of disease, families must deal with a particular level of disability but can't "settle in" at a specific stage or level of impairment because the progression continues. These families experience increasing caregiving and psychosocial burden and strain (Rolland, 1994). This is particularly difficult for mothers as they are usually the primary caregivers for the family.

In an illness with a constant course, there is an initial event, but then the biological condition stabilizes. Examples include amputation, or spinal cord injury with paralysis. The person may face difficulties at times, but the individual and family are faced with a change that is stable and predictable over time. Once the person and family learn how to manage the disability, they can plan for the future without the continual uncertainty inherent in progressive disease.

Conditions with a relapsing or episodic course include asthma, migraine headaches, multiple sclerosis and inflammatory bowel disease to name just a few. This type of course has periods of stabilization followed by periods of flare-up or exacerbation. Families may be able to carry on a normal routine but are always uncertain as to when a "flare-up" may occur which will change their normal way of functioning as a family. In this type of course the family is always "on call" to cope with crises which can occur at unpredictable times. There is considerable psychological discrepancy between periods of normalcy and periods of illness. These disorders may not be as biologically severe as those with a progressive or constant course, yet, over time, they can be the most psychosocially challenging (Rolland, 1994). This is particularly difficult for mothers who tend to be the arranger of family schedules and routines. The uncertainty of when flare-ups will occur can make routine family life unpredictable and stressful.

OUTCOME: The extent to which a chronic illness is likely to cause death or shorten one's life span are also critical distinguishing features with an important psychosocial impact. At one end of the continuum are illnesses that do not affect the life span, such as blindness, arthritis, or seizure disorders. At the other end of the continuum are diseases that are clearly progressive and usually fatal, such as amyotrophic lateral sclerosis, or metastatic cancers. In the middle of the continuum are diseases that are more unpredictable and tend to shorten one's life span. These diseases include cystic fibrosis, juvenile-onset diabetes, and cardiovascular disease.

The major differences between these types of outcomes are the degree to which the family experiences anticipatory loss and their effects on family life. The main concern for families is the degree to which they may experience loss in the family. Families are often caught between intimacy with and distancing from the ill family member.

INCAPACITATION: Chronic illness can lead to disabilities, which range from mild to severely incapacitating. The different kinds of incapacitation will require different adjustments for the family. As the mother is often the pivotal caregiver in the family, increasing or more severe incapacitation of the mother with chronic illness could be devastating to family functioning. In addition, loss of the mother's income, due to incapacitation, could destroy family economic stability, particularly for single mothers living with chronic illness. Lastly, incapacitation could have a negative impact on the mothers' relationship with her spouse/partner as living with chronic illness may result in her not being able to maintain a satisfying marital relationship.

UNCERTAINTY: Rolland (1994) does not list uncertainty as a separate category but suggests that uncertainty is pervasive throughout the above 4 categories and considers it an important psychosocial element of chronic illness. According to Rolland (1994), the more uncertain the course and outcome, the more a family must make decisions with flexible, alternative plans based on the unpredictability of the disease. This requires families to adequately problem-solve, which can exhaust even the most resilient and adaptive families living with illness.

In the last decade, the number of chronic, life-threatening illnesses has continued to increase dramatically. This increase has resulted in a growing interest among nurse researchers, as well as researchers in other disciplines, to study how individuals and families deal with the uncertainty of acute and chronic illness.

Several other attributes, in addition to the basic components of the illness typology, should also be considered in understanding the implications of chronic illness for individual and family adaptation. These attributes include symptom visibility, the likelihood and severity of crises, the role of genetics, and treatment regimens.

SYMPTOM VISIBILITY

Visible signs of illness, although having the potential disadvantage of stigma and shame, do permit others to gauge their interactions in a more objective way than is the case with invisible signs of illness (Rolland, 1994). Invisible signs of illness foster ambiguity in a number of ways. For some family members, it is easier to deny or minimize symptoms that are out of sight, out of mind (Rolland, 1994). For other family members, ambiguity fosters a sense of thinking the worst-case scenario about the family member who is ill, invisible signs of wellbeing not permitting confirmation of health. Invisible symptoms that fluctuate, such as pain, can be used by the ill family member as a way to control family interactions and thus engender a distrust of the ill member by other family members.

LIKELIHOOD AND SEVERITY OF CRISES

Fears about illness-related crises are often a source of anxiety for families dealing with chronic illness. It is important for families to understand how a medical crisis can be prevented as well as how to manage a crisis should one occur. The extent and accuracy of the families' knowledge about the chronic illness should be assessed and health care providers should assist families in planning for such crises.

GENETIC CONTRIBUTION

Another illness variable of psychosocial importance is the family's understanding of the possible role of genetic transmission of a disease. The family's knowledge, the family's cross-generational experience with a particular illness, and family mythologies that have developed in connection with the disease, are important to assess and evaluate (Rolland, 1994). Genetic diseases can provide a powerful focus for blame, self-incrimination, and victimization. Genetic counseling is often an extremely useful part of the treatment plan for families living with a chronic illness that is considered to be genetic.

TREATMENT REGIMENS

Different illnesses require different treatment regimens in regard to complexity. Some illnesses require expensive and difficult to operate equipment. Other illnesses require the assistance of other family members or health care professionals. It is important that the demands of illness fit the family's pattern of functioning if at all possible. A relatively disengaged family will have more difficulty with illnesses requiring regular teamwork with health care providers than with illnesses that require little collaboration with others. The degree of family emotional support, role flexibility, effective problem solving, and communication in relation to the treatment plan are critical predictors of long-term treatment compliance and the appropriateness of home care (Rolland, 1994). It is important for health care providers to assess the ability of the family to carry out specific regimens and to offer information and assistance to families in an effort to promote regimen compliance.

UNCERTAINTY IN INDIVIDUALS WITH CHRONIC ILLNESS

UNCERTAINTY IN ILLNESS THEORY

In the early 1980's Merle Mishel (1981, 1983) began to conceptualize uncertainty in the context of illness as a research construct within a theoretical model of uncertainty appraisal, coping, and adaptation. The theory of Uncertainty in Illness (Mishel, 1988) emerged in the late 1980's and incorporated a number of conceptual ideas from the work on stress and coping by Lazarus and Folkman (1984) as well as research from nursing and related fields. In 1990, Mishel "reconceptualized" the Uncertainty in Illness theory to make it more applicable to chronic illness, as the original theory (Mishel, 1988) was targeted specifically to individuals with acute illness.

Uncertainty was originally defined in Mishel's work as a cognitive state created when an event cannot be adequately structured or categorized because sufficient cues are lacking (Budner, 1962). In addition, uncertainty occurs when the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes (McIntosh, 1976). Uncertainty is generated by events characterized as vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information (Mishel, 1981). Similar to McIntosh's (1976) definition of uncertainty, Mishel (1988a) defined uncertainty in her later work as the inability to determine the meaning of events and suggests uncertainty occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes.

In 1990, Mishel offered an extension of her earlier work on uncertainty to accommodate chronic illness. The Uncertainty in Illness theory was expanded using a method proposed by Walker and Avant (1989) called theory derivation. Theory derivation is defined as a process of using analogy to obtain explanations about phenomena in one field from the explanations about phenomena in another field. Chaos theory was chosen as the parent theory because it deals with relationships between systems in an open system as well as the interaction of the system with outside forces. Concepts in Chaos theory include disorder, diversity, disequilibrium (or far-from-equilibrium), instability, nonlinear relationships, and temporality, all of which are considered part of the healthy variability of a system (Pool, 1989).

According to Pool, a single fluctuation, or a combination of fluctuations, can become so overwhelming within the system that the organization of the system may be shattered. It is at this point the system reorganizes itself in a multitude of ways. Mishel (1990) proposes that the uncertainty surrounding a chronic illness can qualify as a sufficient enough fluctuation to threaten the preexisting organization of the person. As uncertainty continues there is an increase in disorganization and instability, to the point that there is uncertainty even in the meaning of everyday routine events. According to Mishel, even at this highly disorganized state, a new, higher order, more complex state is being formed. The individual begins to accept uncertainty as a way of life and predictability is abandoned as part of the old way of life. Thus, there is a new ability to focus on multiple alternatives, choices, and possibilities, to reevaluate life's priorities, to appreciate life. Thus, uncertainty can become an opportunity for challenge and growth rather than a danger.

Mishel's later theory (1990), which targets individuals with chronic illness, can be summarized as: (1) focusing on the management rather than elimination of uncertainty in order to integrate it into one's view of life with chronic illness; (2) targeting individual's living with continual, constant uncertainty from chronic illness; (3) viewing the process of uncertainty as being a gradual process, beginning as the illness begins to disrupt the individual's life and (4) focusing on the growth that occurs in dealing with uncertainty, with the result being the availability of more choices for the individual with chronic illness.

RESEARCH ON UNCERTAINTY IN CHRONIC ILLNESS

Merle Mishel (1981) developed the first form of the Mishel Uncertainty in Illness Scale (MUIS) to measure uncertainty in ill, hospitalized adults (MUIS-A). Following the development of the MUIS-A scale, three additional uncertainty scales were developed: (1) the community form of the MUIS (MUIS-C) which is used by individuals or by persons or families of chronically ill persons who are not hospitalized and not likely to be receiving medical attention; (2) the Parents' Perception of Uncertainty in Illness (PPUS), which measures the parents' uncertainty experience concerning their child's illness; and (3) the PPUS-FM scale which is an altered form of the PPUS in which the word "child" is changed to spouse, friend, sister, etc. to evaluate the degree of uncertainty experienced by a wife, husband, or family member concerning an ill family member.

Studies using the uncertainty scales have examined a number of variables as **antecedents** of uncertainty. These include severity of illness, the erratic nature of symptomatology, the ambiguity of symptoms, cues and information from health care providers, personal beliefs, characteristics and abilities, social support, and demographic variables (age, marital status, socioeconomic status, employment, and educational level). The erratic nature of symptom onset and disease progression seems to be the major antecedent to uncertainty in chronic illness (Mishel, 1999). Mishel and Braden (1988) found the antecedent severity of illness predicted higher uncertainty levels in a group of women being treated for gynecological cancer. In a later study, Braden (1990) found that illness severity was again a significant predictor of higher uncertainty in a study of patients with rheumatoid arthritis. Studies using the MUIS have also reported that the re-occurrence of the same condition or frequent repeated hospitalizations (aspects of severity) lead to higher levels of uncertainty (Andersson-Stegesten, 1991; Ronayne, 1989; Van Den Borne, 1987; Webster & Christman, 1988). Several researchers (Christman, McConnell, Pfeiffer, Webster, Schmitt, & Ries, 1988; Mishel, 1984; and Wineman et al., 1993) found education to be an antecedent of uncertainty (lower levels of education resulted in higher levels of uncertainty).

A few studies support the association of uncertainty and emotion-focused coping. Redeker (1992) found that ambiguity regarding the illness and complexity surrounding treatment was associated with patients' wishful thinking. A group of 61 women receiving treatment for gynecological cancer were found to use emotion-focused coping to manage the sense of danger associated with higher levels of uncertainty (Mishel & Braden, 1988).

Mishel and Sorenson (1991), in a test of the mediating effects of coping on the relationships between the appraisal categories of danger and opportunity and emotional distress in a sample of 131 women receiving treatment for gynecological cancer, found two coping strategies were significant mediators. One emotion-focused coping strategy, wishful thinking, mediated the effect of danger on emotional distress and one problem-focused coping strategy, focus on the positive, mediated the effect of opportunity on emotional distress.

In examining measures of adjustment, Mishel (1984) found uncertainty to be positively related to disruption in family, problems with continuing recreational interests, and psychological distress in women with gynecological cancer.

In reviewing the literature on uncertainty and chronic illness using the MUIS-C instrument, several studies support the uncertainty in illness theory. The relationship between uncertainty and the nature of illness suggests that there are three areas of the illness that seem to cause uncertainty: (1) severity of illness; (2) erratic nature of symptomatology; and (3) ambiguity of symptoms. Braden (1990) found that severity of illness was a major predictor of uncertainty in patients with rheumatoid arthritis. In 95 men and women with asthma, Janson-Bjerklie, Ferketich and Benner (1993) found dyspnea intensity, perceived illness severity, episode distress and nocturnal dyspnea were significantly positively associated with uncertainty. Other studies, where illness severity was defined as functional ability, reported contrary findings, specifically with women with multiple sclerosis or rheumatoid arthritis (Bailey & Nielsen, 1993; Wineman, 1990).

One of the major antecedents to uncertainty in chronic illness is the erratic nature of symptom onset and disease progression. Becker (1993), in a sample of 95 adults with physician diagnosed and documented asthma, found past experiences with erratic symptoms and prior history with illness did not decrease the uncertainty about how to manage the recurrence of symptoms. Webster and Brennan (1995) reported that women with interstitial cystitis experienced uncertainty about the changing course of the illness, the inability to predict pain severity, and the unpredictability of symptoms which all increased uncertainty regardless of whether the women were in remission, or having mild, moderate, or severe symptoms.

Another source of uncertainty for individuals with chronic illness is dealing with the ambiguity of symptoms. Uncertainty can occur when individuals have difficulty differentiating between symptoms of chronic illness and other body changes. Smeltzer (1994) reported, in a qualitative study of 15 pregnant women with multiple sclerosis, that the development of new symptoms was a source of uncertainty because it was sometimes difficult to differentiate new illness symptoms from unfamiliar body changes due to pregnancy. Hilton (1988) found that women who were breast cancer survivors had similar concerns regarding the identification of symptoms due to chronic illness versus normal body changes, which also led to an increased level of uncertainty.

Concern about the future was associated with increased levels of uncertainty. Qualitative studies, in particular, suggest short and long-range future plans are a source of uncertainty for some individuals living with chronic illness. Smeltzer (1994) reported that pregnant women with multiple sclerosis voiced uncertainties about future parenting issues. Nelson (1996), in a qualitative study, interviewed 9 women survivors of breast cancer and found women were concerned with the possibility of disease recurrence and/or progression and this resulted in increased uncertainty. Pelusi (1997), also interviewing breast cancer survivors, reported that women voiced uncertainty about their ever-changing social and interpersonal roles. Ferrans (1993) reported that among hemodialysis patients with end-stage renal disease, uncertainty about the future ranked as a major source of stress.

Chronic illness can lead to questioning one's own identity, to challenge and change in the concept of self, and to growth and finding new meaning in life. Fleury's (1995) work suggested that women recovering from an acute cardiac event viewed the illness as changing their self-identity and that dealing with uncertainty led them to question their beliefs and values. Numerous qualitative studies support this aspect of the uncertainty theory. Nelson's (1996) hermeneutic phenomenological study of nine women two and six years after treatment for breast cancer described the growth-producing feature of uncertainty. Women expressed a newfound freedom within the uncertainty experience- freedom to express themselves more openly and honestly than they had in the past. These women believed the experience gave them permission to live more healthfully, to change their behaviors, attitudes and lifestyles rather than abiding by socially acceptable norms. Pelusi (1997) reports that women who have survived breast cancer found new meaning in ever-changing roles. Fleury (1995), in a grounded theory approach, reports that women, after experiencing a cardiac event, found psychological healing included working through the uncertainty of the event. Healing occurred as an emerging process that included knowing new aspects of themselves, exploring new possibilities, and reframing their world view as they began to integrate the uncertainty surrounding the cardiac event into their lives. Women struggled to come to terms with and grow through the uncertainty as one way of creating new and positive health behavior patterns. Women attempted to heal themselves through a focus on multiple alternatives and possibilities; a reevaluation of their values and goals; a reassessment of priorities and personal investment; and an appreciation of the impermanence of life situations (Mishel, 1990).

Individuals who reported they needed information to make the future more predictable viewed lack of information as a source of uncertainty. Lack of information led to increased uncertainty in several studies in different populations (Mason, 1985; Moser, Clements, Brecht, & Weiner, 1993; Nyhlin, 1990; Small & Graydon, 1993; Weems & Patterson, 1989). Hilton (1988) suggests uncertainty doesn't decrease over time despite information. In a study examining women four years after the diagnosis of breast cancer, women reported lack of information regarding disease prevention led to increased levels of uncertainty. Mishel (1999) suggests further research in this area is needed regarding the time in which lack of information causes the most uncertainty i.e. at the time of diagnosis, exacerbation, or during daily living.

Findings are inconsistent in the relationships of social support and the role of health care providers to uncertainty. Sources of uncertainty for HIV positive mothers included concerns about whom to tell and how others will respond to their HIV status, as well as how to obtain child care and what will happen to their children if something happens to them (Regan-Kubinski, & Shorts-Hopko, 1995). In a qualitative study of 15 pregnant women with multiple sclerosis, Smeltzer (1994) found women were uncertain as to how others would react to their pregnancy and therefore were more likely to tell others the pregnancy was an accident. Fleury (1995) suggests women are concerned about their personal future and roles when recovering from a cardiac event, which resulted in greater uncertainty for them. In other findings, however, Charmaz(1994) reported that family members' support was important in helping the individual with chronic illness maintain their self-identity. Two quantitative studies found no relationship between social support and uncertainty in individuals with systemic sclerosis (Moser et al., 1993) and multiple sclerosis (Wineman, 1990).

Uncertainty is an issue for family members as well as the individual with chronic illness. One recent study suggests that emotional support and assistance provided by family members is critical to the survival and quality of life in patients with chronic renal disease (Campbell, 1998). Pelletier (2001) reports that when asked to describe what has been the most stressful aspect of living with someone who has end-stage renal disease, uncertainty was a major source of stress as they struggled to deal with the unpredictability associated with four themes: (1) the patient's health, (b) illness treatment, (c) the potential loss of the patient, and/or (d) the availability of a kidney for transplant.

Caregivers of individuals with multiple sclerosis found that uncertainty along with perceived burden were the strongest predictors of caregivers' health impairment and mood (O'Brien, Wineman, & Nealon, 1995). The authors express caution concerning the findings however, due to low subject-to-variable ratio. Wineman (1990) suggested in families where one spouse has multiple sclerosis, higher uncertainty was associated with higher family life dissatisfaction for both spouses. In addition, for the well spouse, the congruence between each spouse's positive perception of the uncertainty was critical in determining the well spouse's positive family satisfaction (Mishel, 1999). Spouses where incongruence existed had lower levels of family satisfaction. In an earlier qualitative study by Rowat & Knafl (1985), researchers reported spouses of individuals with chronic pain found the uncertainty unbearable. In addition, they reported feeling trapped as well as suicidal (Rowat & Knafl).

Findings regarding the role of the health care provider and uncertainty are also inconsistent. Mishel (1992) suggests the difficulty in getting a diagnosis which often occurs with chronic illness leads to an erosion of faith in the physician's judgment which in turn, leads to increased uncertainty. Individuals living with chronic illness often become very knowledgeable and comfortable in managing their disease on a daily basis. They know their own bodies and what works well for them as well as what does not work well. Becker (1993), in a study of adults with asthma, found they did not want to seek medical care during times of crisis for fear of inadequate treatment by health care providers they felt were not as knowledgeable as themselves in caring for their asthma. Pregnant women with multiple sclerosis (Smeltzer, 1994) questioned whether health care providers would be able to differentiate symptoms of multiple sclerosis from normal changes in their bodies due to pregnancy. On the other hand, Affleck (1987), in a study of 92 adults with rheumatoid arthritis, found adults perceived their illness as more predictable when they believed their health care provider had control over the illness. There is a need in this area for more research, perhaps using triangulated studies where both measurement and interview may help clarify the role of both social support and the role of health care providers (Mishel, 1999).

Quantitative studies addressing uncertainty and personality dispositions suggest self-management of chronic illness, including self-efficacy, monitoring and gathering information, all led to a decreased level of uncertainty (Braden, 1990; 1991). Adults with multiple sclerosis were found to have less uncertainty with increased perceived personal control of their illness (Armor, McDermott, & Schiffer, 1996). Moser and colleagues (1993) reported health related hardiness played a role in lessening uncertainty in individuals with systemic sclerosis.

More recent studies suggest a relationship between uncertainty and spiritual wellbeing. Crigger (1996) found spiritual wellbeing led to a decreased level of uncertainty in 90 women diagnosed with multiple sclerosis. Landis (1996) reported spiritual wellbeing acted as a mediator between uncertainty and psychosocial adjustment in 94 individuals with diabetes mellitus.

Numerous studies suggest that uncertainty is a predictor of psychosocial distress. In a study of 81 individuals who had experienced a myocardial infarction in the past three months, high levels of uncertainty were related to more negatively toned emotions (Bennet, 1993). This finding is consistent with work by Christman and colleagues (1988) in that uncertainty is associated with poorer adaptational outcomes and specifically, negatively toned emotions. In a later study, Christman (1990), in a sample of 68 adults receiving radiation therapy for cancer, found greater uncertainty was associated with more adjustment problems.

Hawthorne and Hixon (1994), in a sample of 24 adults with chronic heart failure, found uncertainty related to increased mood disturbances during hospitalization and at 1, 3, & 6 months post-discharge from the hospital. This was consistent with Webster and Christman's (1988) findings in 20 adults at 6-8 days post-discharge following hospitalization due to a myocardial infarction.

In three different studies of adults with multiple sclerosis, uncertainty was associated with increased psychological distress. In 118 adults with progressive multiple sclerosis (Wineman, 1990) uncertainty was positively associated with depression. In 1993, Wineman, O'Brien, Nealon, and Kaskel, studied 61 couples in which one spouse had multiple sclerosis and found uncertainty was positively associated with negative mood states for the family member with chronic illness. In a larger study of 433 individuals with multiple sclerosis and 257 individuals with spinal cord injuries, Wineman, Durand, and Steiner (1994), found uncertainty was negatively associated with emotional well-being.

Qualitative studies, however, found that there was a transition through uncertainty that led to growth and a new way of looking at life and this included accepting uncertainty as part of that new life. These qualitative studies include women surviving treatment for breast cancer (Nelson, 1996; Pelusi, 1997) and women recovering from a cardiac event (Fleury, 1995). Although this process of change through uncertainty is discussed in Mishel's (1990) theory, few of the researchers refer to this theory to support their findings, which is a limitation of the studies.

UNCERTAINTY MANAGEMENT

Numerous researchers have examined methods individuals use to manage the uncertainty of chronic illness. There have been limited findings in quantitative studies regarding uncertainty management (Mishel, 1997). On the other hand, qualitative studies have identified numerous strategies individuals use to manage uncertainty. The major method used to manage uncertainty was to restructure life to include the unpredictability of symptom onset (Baier, 1995; Becker et al., 1993; Small & Graydon, 1993; Weitz, 1989). This restructuring included learning to live one day at a time, being more cautious, pacing themselves, being more aware of signs of danger, and getting to know the illness better (Baier, 1995; Johnson & Morse, 1990; Mason, 1985; Becker et al., 1993; Mishel & Murdaugh, 1987). There is a focus on normalization, on trying to live as normal a life as possible (Robinson, 1993). Using a grounded theory approach, Robinson interviewed 31 adults managing chronic conditions in themselves, their spouses, their parents or their siblings. When first beginning to manage life with a chronic illness, these individuals reported that life was "problem saturated" and they were not leading a normal life. At some point in living with the chronic illness, their life story changed to become a life beyond chronic illness. How did this change occur? The change usually involved reframing or changing the viewpoint as to how a situation is experienced and to view the situation in a better light. Choices are made as to what to include in their new view of life and what to exclude. The result is an evolving story of life "as normal".

Through normalization, uncertainty about life becomes a normal part of life. A critical part of this process is convincing others that life is normal. Individuals have been found to use a variety of methods to achieve this goal including: (1) covering up differences; (2) doing normal activities; (3) desensitization; and (4) making trade-offs (Robinson, 1993).

Although the MUIS-C instrument has been used in a number of studies of individuals with chronic illness, further investigation is warranted. Several studies have reported the effect of nursing interventions on uncertainty (Andersson-Segesten, 1991; Braden, 1992; Hawthorne & Hixon, 1994; McHenry, Allen, Mishel, & Braden, 1993). In two different Intensive Coronary Care Units in Sweden, a Swedish version of MUIS was used to examine the degree of uncertainty of patients (Andersson-Segesten). Sixty patients' experiences of uncertainty were studied in the units, which were in different locations, and with different staffing and nursing routines. The two units were determined to be different in that one unit was considered person-oriented whereas the second unit was more task-oriented in their nursing care. It was hypothesized that patients in the person-oriented unit who received more information and explanations of care would score lower on the MUIS, however, no significant difference between the patients in the two units was found.

Another study examined the effect on uncertainty of nursing interventions to enhance individuals' knowledge and thus illness management. Braden (1992), in a study of 291 individuals with a diagnosis of systemic lupus erythematosus (SLE), found that individuals who attended a series of self-management classes demonstrated significant change in learned response over time. Self-help model variables that significantly contributed to the change were uncertainty, depression, enabling skill, self-efficacy, and self-worth. Uncertainty and depression decreased over time while enabling skill, self-efficacy, and self-worth increased over time. Participants' also demonstrated significant increases in self-help course tied variables of SLE knowledge and both the range and number of rest, relaxation, heat and exercise activities. A limitation of this study was the lack of a control group for comparison.

To date, the majority of research on uncertainty has focused on the ill adult, with little differentiation to gender. In addition, research on uncertainty has focused on individuals with a specific diagnosis versus the use of a noncategorical approach using a psychosocial typology of chronic illness. The scope and complexity of variables linked to uncertainty make comparison and generalizability of study results difficult (Mast, 1995). Mast also suggests continued psychometric development of instruments and greater consistency in operational definitions to strengthen future research.

Uncertainty research demonstrates that uncertainty is a pervasive stressful accompaniment of illness and treatment regimens. In addition, uncertainty influences individuals' coping and adaptive behaviors, as well as psychological functioning. Research is revealing the nature, sources, and implications of uncertainty. Considering the role of the mother in the family unit, there is a great need for future research that examines the role of uncertainty in mothers with chronic illness.

RESEARCH ON FAMILY HARDINESS

Few studies have looked at the role of family variables, such as family hardiness, in relation to uncertainty and psychological wellbeing. Family hardiness, as a concept, was guided by the conceptualization and research on individual hardiness, developed from the discipline of existential psychology by Kobasa (1979a). In 1979, two researchers began identifying and investigating new concepts that attempted to explain why some individuals are impervious to the debilitating effects of stressful life events (Antonovsky, 1979; Kobasa, 1979a). These two concepts came to be known as the Hardy Personality (Kobasa, 1979a) and the Sense of Coherence (Antonovsky, 1979). Kobasa defined individual hardiness as a personality characteristic encompassing both cognitive and behavioral components, which acts as a stress resistance resource. Kobasa and others (Kobasa, 1979a, 1979b, 1982a, 1982b; Kobasa, Maddi & Courington, 1981; Kobasa, Maddi, Puccetti & Zola, 1985; Kobasa, & Puccetti, 1983) have suggested the hardiness characteristic decreases or buffers the illness-related effects of stressful life events. Hardy individuals have a general sense of meaningfulness about their lives both in terms of having distinguishable personal goals and a feeling of self-involvement and a sense of community (commitment). Hardy individuals view change as a normal aspect of life and a challenge to further development rather than a burden (challenge), and they believe they can control or influence experiences and life events (control). These cognitive aspects are combined with behavioral indicators which suggest the hardy individual takes action to learn more about life's changes, transforms events in order to learn from them, and incorporates them into an ongoing life plan (Kobasa et al., 1981).

In the original study on individual hardiness, Kobasa (1979a) focused on characteristics that distinguished a group of male executives who resisted illness (n=86) from those who became ill while experiencing equally high levels of stress (n=75). Kobasa's results suggested that resistant individuals possess the personality characteristic of hardiness which consists of three components: (1) control- the tendency to feel and act as if one can influence life events; (2) challenge- the belief that change rather than stability is normal in life and that change is an incentive to growth; and (3) commitment- the tendency to involve oneself in all activities of life.

Since Kobasa's original work, a 3-year prospective study was conducted with 670 middle- and upper-level management personnel that yielded similar results (Kobasa, Maddi & Kahn, 1982). Managers completed the questionnaires over a period of five years. Results support the hypothesis by showing main effects on illness for both stressful life events and hardiness and an interaction effect for these independent variables. Following this, several studies were conducted examining the interactive effects of hardiness and other variables. These studies included the interaction of hardiness and exercise (Kobasa, Maddi, & Puccetti & Zola, 1985); predisposition to illness (Kobasa, Maddi, & Courington, 1981); social support (Kobasa & Puccetti, 1982; Lambert, Lambert, Klipple, & Mewshaw, 1989; and Pagana, 1990); Type A behavior (Kobasa, Maddi, Puccetti & Zola, 1985); and health related hardiness (Pollock, 1986, 1989; Pollock, Christian & Sands, 1990). In all these studies, hardiness exerted a direct negative effect on illness and interacted with stress to buffer the effects of stress.

Criticism of Kobasa's early work included concerns regarding the inclusion of all three components, challenge, control and commitment, in the conceptualization of hardiness. The challenge component has not operated as hypothesized in all studies and some researchers have suggested that it not be included in the measurement of hardiness (Hull, Van Treuren & Virnelli, 1987; Rich & Rich, 1987). A second concern regarding Kobasa's work is in the method of measuring the personality dispositions of hardiness. Kobasa used instruments that measured the reverse, or absence of hardiness. For example, in the case of commitment, the Alienation From Self and Alienation from Work scales of the Alienation Test (Maddi, Kobasa, & Hoover, 1979) were employed as negative indicators. Control was measured negatively by the External Locus of Control Scale (Rotter, Seeman, & Liverant, 1962) and the Powerlessness Scale of the Alienation Test (Maddi et al., 1979). The challenge disposition was also measured negatively, by the Security Scale of the California Life Goals Evaluation Schedule (Hahn, 1966) and the Cognitive Structure Scale of the Personality Research Form (Jackson, 1974).

DEVELOPMENT OF FAMILY HARDINESS

Family hardiness was developed from the concept of individual hardiness. Family researchers from various disciplines have often questioned why some families do well in the face of stressful life events while other families have difficulty coping and adapting to stressful events in their lives. Family hardiness focuses upon the family's patterned approach to life's hardships and its typical pattern of appraising the impact of life events and changes on family functioning. In early research, hardiness was thought to have four interrelated components: (1) co-oriented commitment or working together to manage difficulties; (2) confidence in being able to handle problems; (3) emphasis on viewing hardships as challenges and the seeking of new life experiences as challenges; and (4) a sense of internal control rather than being the victim of circumstances (McCubbin & McCubbin, 1993; 1996).

More recently, it has been found the three components of commitment, challenge, and control adequately explain the concept of family hardiness, and, in fact, are stronger psychometrically than the original four component approach, though both approaches have strong reliability and validity (McCubbin, M.A., et al., 1996).

Although most of the hardiness literature has focused on the individual, research has been conducted on the concept of family hardiness as well in samples of families with a child with chronic illness. One study examined the association of family hardiness, stressors, and other variables with family functioning in 57 families of children with developmental disabilities (Failla & Jones, 1991). Significant positive relationships were found between family hardiness and the measures of family coherence, functional support, and satisfaction with family functioning. Family hardiness, functional support, family stressors, and parental age accounted for 42.7 % of the variance in family functioning.

In a sample of 27 families of children ages 1-5 with asthma, Donnelly (1994) found a positive significant relationship between family hardiness, family type, and cohesion and adaptability. More recently, in a sample of 76 families of children ages 1 month to 6 years with asthma, Svavarsdottir, McCubbin & Kane (2000) found that parents' sense of coherence and family hardiness had direct effects on the wellbeing of parents of a child with asthma. In this study, sense of coherence and family hardiness, separately and in combination, moderated effects of both family system and caregiving demands on general wellbeing in mothers and fathers.

In a study of individuals (N=65) caring for an elderly family member, family hardiness was significantly and positively related to family wellbeing (Fink, 1995). In addition, Fink reported family hardiness to be negatively related to family strains. Lustig (1995), examining parents (N=117) of adult children with mental retardation who were beginning supported employment, found a significant positive relationship between family hardiness and family adaptation.

Family hardiness was measured from the perspective of both patient and caregiver in 44 families with an adult family member receiving complex home health care (McCubbin, M.A. 1989). Family hardiness was significantly related to mastery of the home care regimen. There was no significant difference between patient and caregiver measures of family hardiness and no difference between Time 1 and Time 2 measures one month apart. No differences in hardiness were found as a function of diagnosis (McCubbin, M.A., 1989).

In a study of 856 rural families faced with economic hardships, family hardiness was significantly related to both employee and spousal wellbeing during and after the crisis (McCubbin, H.I. 1989). In a national study of 222 families faced with a major occupational and financial crisis, family hardiness was a significant predictor of the employee's job satisfaction after the crisis and in explaining the spouse's emotional distress during the crisis situation. In this study, family hardiness was a critical variable in discriminating between minimally and optimally adapted families as measured by family system distress, work stress effects on the marital and parent/child relationships and family system well-being (McCubbin, M. A., 1989).

McCubbin, H.I. and Thompson (1992), in a study of 200 multiracial families, which included Caucasian, Asian, Hawaiian, and mixed race families, reported family hardiness was significantly related to family wellbeing for all ethnic groups. In a later study of Native

Hawaiian families (N=155), McCubbin, H.I., Thompson, Thompson, Elver, and McCubbin, M.A. (1994), reported family hardiness was a negative predictor of family incendiary communication & family dysfunction.

The significant findings related to family hardiness are consistent with previous research on individual hardiness showing that hardiness acts as a stress resistance resource, which buffers the effects of stress and facilitates adaptation at both the individual and family level. Future research needed in this area includes replication of studies, including studies of families who have a mother living with chronic illness. The majority of research in this area thus far has focused on children rather than other family members with chronic illness. To date, this author was not able to find a single study examining family hardiness in families of mothers with chronic illness.

RESEARCH ON PSYCHOLOGICAL WELLBEING

SELF-IMAGE, PHYSICAL LIMITATIONS AND PSYCHOLOGICAL WELLBEING

Mothers with chronic illness are faced with many additional changes and challenges including new health demands, financial concerns, lack of definitive information about the condition, and child care issues to name a few. Several studies on mothers with chronic illness reflect mothers' concerns with physical limitations, fatigue and stamina, bladder control, and memory (Monroe, 1989; Smeltzer, 1994; & Thorne, 1990), all of which influence the mothers' ability to effectively master the environment in which she lives, thus possibly impacting her self-image and psychological wellbeing. Mukherjee (2002), in a study of 5 fathers and 19 mothers with inflammatory bowel disease, reported when parents were experiencing symptoms of their chronic illness, there were difficulties caring for young children, problems taking children to and from school, and attending school events; restrictions in social life; irritability and reduced tolerance of children. Strategies commonly used by the parents in Mukherjee's study included turning to family members for support and trying to control the symptoms of their illness.

Lewis and her colleagues (Lewis, Hammond, & Woods, 1993), using family systems theory as a guiding framework, found that increased demands of illness led to higher levels of depression in both mothers and their partners, which in turn led to decreased marital adjustment. In addition, Woods & Lewis (1995), also using family systems theory to guide their work, found women who experienced more demands with increased duration of illness reported more depressed mood. Unfortunately, in both of the Lewis and Woods articles, the authors are looking at "women" and don't specify whether or not these women are mothers; however, based on the age of the women in the studies, most certainly some were mothers.

In an effort to assist mothers living with chronic illness, health care providers can help by providing support and information about parenting with chronic illness. Unfortunately, Smeltzer (1994) and Thorne (1990) identified a lack of support and information available from health care providers for families living with chronic illness.

PERSONAL GROWTH AND PSYCHOLOGICAL WELL-BEING

Mothers with chronic illness may not be able to experience personal growth in the same way they experienced it before or had planned to continue to grow in the future. On the other hand, some mothers felt dealing with the experience of chronic illness resulted in their families becoming more understanding, more empathetic, and compassionate toward others (Rehm & Catanzaro, 1998). One positive consequence, Rehm and Catanzaro report, is that one parent spent more time with the children than he or she would have had chronic illness not been a part of their lives. Parents especially mentioned the extra time spent by fathers who were spending more time with their children because their wives were not always able to drive or attend all their children's activities.

Interestingly, there is very little research in the area of personal growth for mothers living with chronic illness. It may be the role of motherhood in our society that suggests it is not as important for mothers to be concerned with their own personal growth as it is to be concerned with the family as her first priority. Feminist theorists have continually questioned the nature of motherhood, grappling along the way with the emotional perceptions, persistent ideologies, and the actual experiences of mothers (Osmond & Thorne, 1993).

AUTONOMY AND PSYCHOLOGICAL WELL-BEING

Mothers with chronic illness may feel less autonomy and more reliance on family members and friends for support as well as physical care. Parents and children both perceived that chronic illness often led to increased responsibility and workload for the spouse without chronic illness in the areas of parenting, financial support, and household chores (Rehm & Catanzaro, 1998). Other family members, potentially resulting in mothers experiencing a loss of self-identity, assume tasks previously performed by the mother.

Reliance on health care providers for care including support and information decreases the mother's autonomy if health care providers don't empower the mother, as well as other family members, with the knowledge and the means to care for herself as much as physically possible.

FAMILY RELATIONSHIPS AND PSYCHOLOGICAL WELL-BEING

The importance of positive relations with others is repeatedly stressed in life span literature as well as psychosocial and family studies literature. The relationship of the mother to the rest of her family, particularly when she is chronically ill, has been examined in a number of studies.

For mothers, one of the main purposes in life is raising children. Thorne (1990) suggests that women with chronic illness must constantly strive to resolve the inherent conflict between the roles of effective mother and good patient. Monroe (1989) found that most chronically ill mothers considered parenting to be a positive and satisfying experience, despite feelings of guilt and frustration around their limitations.

Often, marriage is affected in a number of ways when the mother is chronically ill. Several studies have examined the effects of chronic illness on marriage. Woods & Lewis (1995) found that increased demands of illness led to higher levels of depression in parents, which in turn led to decreased marital adjustment. In addition, partners in poorly adjusted marriages were not able to reflect on their behavior and alter it as needed, decreasing the level of introspective coping behaviors. The authors found marital adjustment affected every aspect of family life: family coping, the children's psychosocial functioning, parent-child relationships, and family functioning. Families with higher levels of coping behaviors had overall higher functioning, and the children had better psychosocial adjustment. Lewis, Woods, Hough & Bensley (1989) found that mothers with better marital adjustment had more frequent exchanges with their children. This suggests that poor marital adjustment can negatively affect parenting for mothers with chronic illness.

In a sample of 48 fathers with young school-age children whose wives had breast cancer, diabetes, or fibrocystic breast disease, the number of illness demands the father experienced was a significant predictor of his level of depression (Lewis et al., 1989). More demands resulted in higher depression scores. Marital adjustment was significantly affected by both the father's level of depression as well as by his wife's disease type. Spouses of women with breast cancer had significantly higher levels of marital adjustment than did partners of other women. More depressed spouses had lower levels of marital adjustment.

Woods and Lewis (1995) found the number of demands associated with the illness-produced problems with marital adjustment. In addition, her study suggests introspective coping behaviors were used more frequently by families in which the women experienced high marital adjustment but depressed mood. Woods suggests that a strong relationship with an adult partner may buffer the negative effects of depressed mood. Woods also found that the mother's relationship with her children was positively influenced by better marital adjustment and that family functioning was optimum when the family frequently engaged in introspective coping behavior, when the women had low levels of depressed mood, and when marital adjustment was positive. Woods and Lewis' (1995) finding that women's depressed mood interfered with family functioning but not with the maternal-child relationship is not consistent with other work examining mothers' depression to child well-being (Peters and Esses, 1985). Woods suggests perhaps women experiencing depressed mood in response to chronic illness may be able to keep their depression from affecting the quality of their relationship with their children. This may be viewed as another "normalization" strategy as described by Robinson (1993).

In a longitudinal study of 23 families in which one of the parents had multiple sclerosis, Rehm and Catanzaro (1998) examined family members' perceptions of the effect of chronic illness on parenting. Using a symbolic interactionism framework, Rehm and Catanzaro suggest both parents and children mostly thought of their family as functioning well, despite the many changes brought about by the chronic illness of a parent. The goal of family life for these families was to make life as normal as possible. Parents cited a positive attitude and a supportive spouse as contributing to successful parenting and family life. These results again point to the importance of normalization to these families.

NORMALIZATION AND PSYCHOLOGICAL WELL-BEING

Stetz (1994), using a family systems framework, examined 128 families in which the mother was diagnosed with chronic illness. Families were interviewed in their homes using the Problem-Centered Family Coping Inventory (Lewis, Woods, & Ellison, 1983). This study found family system goals are relatively enduring in these families and were not readily affected by illness disruption, suggesting families and individuals continue to have a purpose and goal in life despite the event of chronic illness.

Knafl, Breitmayer, Gallo and Zoeller (1986) conducted a concept analysis of normalization and concluded that four criteria must be met to define this family phenomenon: (1) acknowledge the existence of the disability; (2) define family life as essentially normal; (3) define the social consequences of the situation as minimal; and (4) engage in behaviors designed to demonstrate the essential normalcy of their family life to others outside the family. Research conducted by Rehm and Cantanzaro (1998) on families with parental (either mother or father) chronic illness support this conceptualization, as did research by Robinson (1993), also on parental chronic illness.

Robinson (1998), using a grounded theory approach, interviewed 14 family members about what happens to and for women when a chronic illness enters the family. In this study, the mothers were living with chronic illness themselves, or were caregivers of a family member living with chronic illness. Analysis resulted in a four-stage theory of women's evolving relationships with the family member called "chronic illness". The four-stages include: (1) Stage 1- women, families, and chronic illness; (2) Stage 2- women falling down and falling apart; (3) Stage 3- helping them that help themselves and (4) Stage 4- taking charge of one's life.

In stage 1, initially chronic illness is considered a stranger who invades family life. At some point, however, the illness changes from being a stranger to becoming an unwelcome family member (Robinson, 1998). Women, whether they were ill or not, became the person in the family responsible for protection of all family members from the illness. Robinson reported that women protected all the family members except themselves, even going as far as concealing or not revealing their own experiences with illness.

Interestingly, in all five families Robinson interviewed, the women experienced numerous pressures in addition to the chronic illness which included pregnancy, childbirth, job changes, moves, caring for other children, caring for aging parents, employment outside the home, absence of support, and extended-family problems. Even with the additional burdens, women continued to focus on the other members of the family, to the point of having little if any time for themselves. Often, the women's needs were ignored to the point that they lost touch with themselves (Robinson, 1998). Robinson reports the most common problems these women faced were exhaustion, isolation, and lack of respite.

In stage two, women found themselves "falling down and falling apart" (Robinson, 1998). It is at this point women experienced some illness-related loss that, in addition to other stressors, caused them to "fall down". Losses included: (1) loss of the illness. In this case, once the illness was gone, or less severe, the mother no longer had to be strong and thus at that time fell apart; (2) loss of the future; (3) loss of the sense of family intactness; and (4) loss of family support. Robinson (1998) reported that once these women fell down, there was no one there to pick them up. This lack of family support was devastating to these women. Family members stated they knew something was wrong but didn't realize how serious the problem was or that the women needed assistance. It was at this point family members began to redefine their chronic illness and work through their experiences of living with chronic illness with the assistance of the Family Nursing Unit, an outpatient research and education unit for families experiencing serious chronic illness (Wright, Watson, & Bell, 1990). Families became aware of their strengths and resources and the outcome was a new story of life with chronic illness (Robinson, 1998).

In stage three, women began the work of change with the help of professional nursing interventions. Women entered this stage committed to the idea of change. The two major components of therapeutic change included (1) enabling healing: creating the circumstances for change; and (2) moving beyond and overcoming problems. Women responded that two relationships were helpful to create circumstances for change. First, it was important that the family members come together in concern about the problem, and then it was important to develop a relationship between themselves and the nurse. These relationships created the circumstance for change.

In order to move beyond and overcome their problems, women felt being able to talk freely with their family and the nurse was the first critical step for families. Often these women had intentionally not talked openly with their families as a way to protect their families from the influence of chronic illness.

The nursing team paid particular attention to the family's strengths, resources and possibilities, which families felt were an important part of the process which they called the "noticing of positive things"(Robinson, 1998). This attention to positive things proved to be a powerful influence on the women's self of sense.

Stage Four begins with women and families taking charge of life. The women had a new sense of themselves as strong and resilient with a clear sense of their own limits. Families became more supportive of each other, and according to Robinson (1998) it was the emotional support of family members that had the most powerful influence on the women's sense of wellbeing. Families remained united and the women began to have more options when making life choices.

A limitation of Robinson's (1998) work is the small sample size of five families (14 family members). Despite the small sample size, Robinson's research is useful for understanding families making of arrangements in the context of chronic illness. Regardless of the mother's health status or work outside the home, mothers shoulder the burden of housework. Thus, illness arrangements continue to revolve around mothers and their work.

Health care practitioners need to be aware that mothers, especially mothers who are dealing with chronic illness themselves, need time for reflection and care of themselves in order to be able to care for others.

The number of individuals with chronic illness is increasing and it will be critical to understand the relationship between uncertainty, family hardiness and psychological wellbeing in mothers with chronic illness and their spouse/partner in order to develop interventions aimed at promoting the health of families living with a mother with chronic illness.

RESEARCH HYPOTHESES

Based on Family Systems Theory (Whitchurch & Constantine, 1993) and the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993; 1996), and the limited research literature on mothers with chronic illness, the following hypotheses will be tested:

For both mothers and their spouse/partners:

(1) antecedents of uncertainty (education and severity of illness) will be negatively related to uncertainty;

(2) uncertainty will be a significant negative predictor of psychological wellbeing;

(3) family hardiness will be a significant positive predictor of psychological wellbeing;

(4) family hardiness will function as a moderator between uncertainty and psychological wellbeing; and

(5) congruence between mothers' and spouse/partners' levels of uncertainty and family hardiness will be a significant positive predictor of psychological wellbeing.

Chapter IV

Methodology

Research Design. This study used a cross sectional correlational design. Data for the study was obtained from mothers and their spouse/partners in families where the mother was living with chronic illness and there was at least one child under the age of 18 still living at home. Patient criteria included the ability to read and write English and the lack of any disability that would prevent their completing the scale. Mothers and spouse/partners were asked to sign consent forms, complete demographic questionnaires and three instruments: (1) Uncertainty in Illness Scale- Community version; (2) Family Hardiness Index; and (3) Psychological Well-being Scale. Mothers were asked to complete two additional instruments: (1) Mother's Illness Information and (2) Life with Chronic Illness questionnaire. Lastly, mothers and their spouse/partners were asked to complete three open-ended questions about living with chronic illness.

Sample Description. Eligible families were recruited from several sources including university-affiliated clinics, chronic illness support groups, and a university affiliated Women's Health Center in an upper midwestern section of the United States. For this study, a noncategorical approach to chronic illness was used. Drawing on Rolland's (1994) psychosocial typology of chronic illness, chronic illness was defined as an illness that is gradual in onset, relapsing/episodic in its course, and mild to moderately incapacitating. Thus, this sample included mothers with chronic illnesses such as rheumatoid arthritis, migraines, multiple sclerosis, diabetes and fibromyalgia. In addition, spouses/partners of the mothers with chronic illness were asked to participate in the research study.

Sixty mothers and 30 fathers representing 60 families, met the study criteria, agreed to participate, and returned their completed questionnaires. Data collection lasted 15 months, beginning May 2001 and ending August 2002. One hundred and fifteen families received the research questionnaires either from the principal investigator or from nurses at the study sites. Families returned the completed questionnaires to the principal investigator in a self addressed stamped envelope. The mothers' response rate was 52%; of those mothers having a spouse/partner, 71% (n = 30) of those spouse/partners participated in the study.

Based on a small to moderate effect size of 0.10, it was determined a sample size of 60 subjects would result in a power of .81 (J.Henriques, personal communication, September 29, 2000).

Parent Demographic Information.

The mean age of the 60 mothers was 40.9 (SD = 6.84), with a range of 28 - 55 years. Spouse/partners (N = 30) mean age was 41.67 (SD = 6.78), with a range of 30 - 60. Mothers' mean education was 15.4 years (SD = 2.22), with a range of 12 - 22 years; and the mean education for spouse/partners was similar at 16.2 years (SD = 2.09) with a range of 12 - 21 years (See Table 1).

Table 1

Descriptive Statistics for Parents' Age and Education

Category	Mothers (N = 60)			Spouse/partners (N = 30)		
	Mean	(SD)	Range	Mean	(SD)	Range
Age	40.9	(6.84)	28-55	41.67	(6.78)	30-60
Education (years)	15.4	(2.22)	12-22	16.2	(2.09)	12-21

Twelve mothers (20%) and 2 spouse/partners (6.7) had a high school education; one additional mother had received her GED. Thirteen mothers (21.7%) and 7 spouse/partners (23.3%) had intermediate or associate degrees. Twenty-two (36.7%) mothers and 13 (43.3%) spouse/partners had bachelor degrees. A master's degree or higher level of education was reported by 12 mothers (20%) and 8 spouse/partners (26.6%) (See Table 2).

Of the 60 mothers, 12 (20.3%) were not working outside the home. Eight (13.6%) worked part time, 32 (54.2%) worked full time, and 7 (11.9%) worked full time and a second job.

The majority of spouse/partners worked full time (20 or 66.7%). One spouse/partner (3.3%) worked part time and 9 spouse/partners (30%) worked full time and a second job. None of the spouse/partners were unemployed (See Table 2).

All of the spouse/partners (30 or 100%) were Caucasian. Of the mothers, 58 out of 60 (96.7%) were Caucasian, 2 (3.3%) were African-American (See Table 2).

Most of the mothers (33 or 55%) and spouse/partners (28 or 93.3%) were married. One spouse/partner (3.3%) was divorced and remarried compared to 7 (11.7%) mothers. One mother was cohabiting (1.7%), as was 1 father (3.3%). Twelve (20%) mothers were divorced, four (6.7%) were widowed, one mother (1.7%) was widowed and remarried and two mothers (3.3%) were single (See Table 2). Mothers had been married or in a relationship an average of 12.7 years (SD = 6.35) with a range from 3 to 25 years (See Table 3). Spouse/partners had been married or in a relationship an average of 12.92 years (SD = 6.57) with a range of three to 25 years (See Table 3).

Family Demographic Information

Twelve mothers (21.8%) did not have any children from the present marriage, fifteen mothers (27.3%) had one child, eighteen mothers (32.7%) had two children, seven mothers (12.7%) had three children and three mothers (5.5%) had four children (Table 3). Twenty three mothers (37.4%) had child(ren) from a prior marriage (See Table 3).

Two spouse/partners (6.7%) did not have any children from the present marriage, eleven spouse/partners (36.7%) had one child, twelve spouse/partners (40.0%) had two children, three spouse/partners (10.0%) had three children and two (6.7%) had four children (See Table 3). Seven spouse/partners (23.3%) had child(ren) from a prior marriage (See Table 3).

The median income for these families was $60,000 - $65,000 with a range of $0 – $5,000 to over $65,000 per year (See Table 3).

Table 3

Family Demographic Frequencies (N = 60)

Category	Mother (N=60)		Spouse/Partner (N=30)	
	n	%	n	%
Length of Marriage/relationship (years)*a				
1-5	7	16.7	4	13.3
6-10	9	21.5	8	26.7
11-15	14	33.3	9	29.9
16-20	5	12.0	4	13.2
over 20	7	16.8	5	16.6
Number of children/present marriage				
0	12	21.8	2	6.7
1	15	27.3	11	36.7
2	18	32.7	12	40.0
3	7	12.7	3	10.0
4	3	5.5	2	6.7
Number of children/prior marriage				
0	37	62.7	23	76.7
1	8	13.6	3	10.0
2	9	13.6	2	6.7
3	5	8.5	1	3.3
4	1	1.7	1	3.3

Mother's Illness Information

Thirty of the mothers were diagnosed with fibromyalgia (50%), 12 with diabetes (20%), 7 with multiple sclerosis (11.7%), 6 with irritable bowel syndrome (10%) and 5 with migraine headaches (8.3%) (See Table 4). The mean length of time from the first symptom to the when the mothers were diagnosed with chronic illness was 48.12 months (SD = 63.37), with a range from less than a month to 31 years. Forty percent had waited from 1 – 2 years since symptom onset to diagnosis. The mean age of the mother when she was diagnosed with chronic illness was 31.57 years (SD 10.11), with a range from 8 to 48 years (See Table 4). Almost half (48.3%) of the mothers (n = 29) were diagnosed between the ages of 31 – 40 years.

Seventeen mothers (28.8%) had visited their health care provider twice for regular checkups in the last year, 14 mothers (23.7%) had made one visit to their health care provider for a regular checkup. Seven mothers (11.7%) had made 4 visits to their health care provider for a regular checkup, eleven mothers (18.6%) made three visits, 4 (6.8%) made five visits, and one mother (1.7 %) made 6 visits, another (1.7%) made ten visits, and another (1.7 %) made 15 visits for regular checkups in the past year. Three mothers (5.1%) had not made any visits for regular checkups in the past year. The frequency of regular checkups in the last year ranged from zero to 15 (See Table 4).

Seven mothers (11.7%) had not visited their health care provider for symptoms in the past year. Ten of the mothers (16.7%) had 3 visits to their health care provider for symptoms of chronic illness in the last 12 months, another ten mothers (16.7%) had 4 visits to their health care providers for symptoms of chronic illness in the last 12 months, nine mothers (15%) had 5 visits for chronic illness symptoms, and 8 mothers (13.3%) had 6 visits for symptoms of chronic illness in the past year. The frequency of visits to their health care providers for symptoms of chronic illness in the last year ranged from zero to 42 (See Table 4).

Forty-nine of the mothers (81.7%) had not required hospitalization for their chronic illness or for any other reason in the last year. Ten mothers (16.7%) were hospitalized once for chronic illness during the last year, one mother (1.7%) had been hospitalized three times for chronic illness in the last year (See Table 4). Nine mothers (15%) had been hospitalized during the past year for non-chronic illness related reasons. One mother (1.7%) had been hospitalized twice during the past year for reasons other than chronic illness and one mother (1.7%) had been hospitalized three times for reasons other than chronic illness in the past year (See Table 4).

All of the mothers were taking at least one prescription medication for their chronic illness. Eleven mothers (18.3%) were taking one prescription medication, fifteen (25%) were taking two prescription medications, 13 mothers (21.7%) were taking three prescription medications, six mothers (10.0%) were taking four prescriptions, four mothers (6.7%) were taking five prescriptions, and eight mothers (13.3%) were taking a total of six prescription medications (See Table 4). The mean number of prescription medications taken for chronic illness was 3.2 (SD = 1.99) (See Table 4).

Nineteen mothers (31.7%) were taking one over the counter medication, thirteen mothers (21.7%) were taking two over the counter medications, and twelve (20%) were taking three over the counter medications. Six mothers (10%) were taking four over the counter medications, and four mothers (6.7%) were taking five over the counter medications (See Table 4). Five mothers (8.3%) were not taking any over the counter medications. Total number of medications taken ranged from 1 – 14 with three mothers (5.0%) taking 12 medications total (See Table 4).

Table 4

Mother's Illness Information Frequencies (N = 60)

Category	N	%
Diagnosis		
Fibromyalgia	30	50.0
Diabetes	12	20.0
Multiple Sclerosis	7	11.7
Irritable Bowel Syndrome	6	10.0
Migraine Headaches	5	8.3
Length of time from 1st symptom to diagnosis		
Less than one year	12	20.0
One to two years	24	40.0
Three to five years	7	11.7
Six to nine years	10	16.6
Ten to twelve years	5	8.3
Over twelve years	2	3.3
Age at time of diagnosis (years)		
5-10	2	3.3
11-20	9	15.0
21-30	10	16.7
31-40	29	48.3
41-50	10	16.7

a Mean length of time from 1st symptom to diagnosis = 48.12 months (SD = 63.37) with a Range of less than one month to 31 years. Mean age at time of diagnosis = 31.57 (SD = 10.11) with a range of 8 to 48 years.

Table 4 continued
Mother's Illness Information Frequencies (N = 60)

Category	N	%
Number of visits to health care provider for regular check-ups in last 12 months		
0	3	5.1
1.0	14	23.7
2.0	17	28.8
3.0	11	18.6
4.0	7	11.9
5.0	4	6.8
6.0	1	1.7
10.0	1	1.7
15.0	1	1.7
Number of visits to health care provider for symptoms of chronic illness in last 12 months		
0	7	11.7
1	1	1.7
2	5	8.3
3	10	16.7
4	10	16.7
5	9	15.0
6	8	13.3
7	1	1.7
8	4	6.7
10	1	1.7
15	1	1.7
21	1	1.7
24	1	1.7
42	1	1.7
Number of times hospitalized for chronic illness in the last 12 months		
0	49	81.7
1	10	16.7
3	1	1.7
Number of times hospitalized for reasons other than chronic illness in the last 12 months		
0	49	81.7
1	9	15.0
2	1	1.7
3	1	1.7

Table 4 continued
Mothers Illness Information Frequencies (N = 60)

Category	N	%
Number of medications for chronic illness prescribed by health care provider		
1	11	18.3
2	15	25.0
3	13	21.7
4	6	10.0
5	4	6.7
6	8	13.3
8	2	3.3
9	1	1.7
Number of over the counter medications used to manage chronic illness		
0	5	8.3
1	19	31.7
2	13	21.7
3	12	20.0
4	6	10.0
5	4	6.7
6	1	1.7
Total number of medications		
1	2	3.3
2	7	11.7
3	12	20.0
4	5	8.3
5	7	11.7
6	6	10.0
7	5	8.3
8	5	8.3
9	8	13.3
10	1	1.7
12	1	1.7
14	1	1.7

Table 4 continued
Mothers Illness Information Frequencies (N = 60)

Category	N	%
Use of complementary therapies to manage chronic illness		
Yes	58	96.7
No	2	3.3
Type of complementary therapy used to manage chronic illness		
Vitamins/Nutritional therapy	40	66.7
Exercise (T'ai Chi, walking)	36	60.0
Mind/body work**	30	50.0
Spiritual care	28	46.7
Massage	20	33.3
Herbal therapy	17	28.3
Chiropractic	15	25.0
Acupuncture	9	15.0
Acupressure	7	11.7
Aromatherapy	7	11.7
Other***	5	8.3
Total number of complementary therapies used to manage chronic illness		
0	2	3.3
1	8	13.3
2	9	15.0
3	13	21.7
4	10	16.7
5	6	10.0
6	6	10.0
7	3	5.0
8	3	5.0

* N varies due to missing data

** Instrument listed relaxation techniques, guided imagery and meditation as examples.

***Mothers listed humor, support groups, physical therapy, and yoga as complementary therapies.

Instruments.

Mothers completed Family Demographics, Mother's Illness Information, Life with Chronic Illness Scale, Uncertainty in Illness Scale, Family Hardiness Index, Psychological Wellbeing Scale and three open-ended questions about life with chronic illness. Spouse/partners completed Family Demographics, Uncertainty in Illness Scale, Family Hardiness Index, Psychological Wellbeing Scale and three open-ended questions about life with a mother living with chronic illness.

Family Demographics. Information on mothers' and spouse/partners' age, education, occupation, employment status, marital status, income, family size, and the number and age(s) of children was obtained (See Appendix A).

Mother's Illness Information. Mother's date of onset of symptoms, diagnosis, date of diagnosis, and age at diagnosis was obtained. Mothers were asked the number of times they sought health care for their chronic illness in addition to regular check-ups and the number of times they had been hospitalized for their chronic illness and for other reasons during the past year. Number of prescription and over the counter medications mothers were taking was obtained as well as the use, type and number of complementary therapies mothers used to manage their chronic illness (See Appendix B).

Severity of Illness. The degree to which chronic illness interferes with life often depends on the severity of illness. Mothers were asked how their lives had changed since being diagnosed with chronic illness. A modification of the Family Inventory of Life Events and Changes Scale (FILE) (McCubbin, H.I., Patterson, & Wilson, 1983) and the Family Change Index (FCI) (McCubbin, M., 1999) was used to measure mothers' severity of illness. The Family Inventory of Life Events and Changes Scale (FILE) was developed as an index of family stress and assesses the pile-up of life events experienced by the family within the past year. The overall reliability for the Family Inventory of Life Events and Changes was .72. The Family Change Index (FCI) was developed as an index of family changes and was used to measure changes experienced by families providing home care to a child living with cancer. The overall reliability for the Family Change Index was .81 for mothers and .94 for fathers. The Life with Chronic Illness Scale (See Appendix C) is an instrument that was developed for this study to measure severity of illness. Respondents were asked to circle one of four choices to indicate the degree to which chronic illness interferes with their life. The 11-item instrument was constructed on a four-point Likert scale format ranging from "better" to "worse". Three of the 11 items on the Life with Chronic Illness scale were derived from the Family Change Index (McCubbin, M., 1999)), and two were derived from the Family Inventory of Life Events instrument (McCubbin, H.I. et al., 1983). The scale was reviewed by three doctorally prepared faculty to check for clarity and wording of questions. The total score for the Life with Chronic Illness scale is obtained by simply summing the number circled by the respondent (i.e., 1 = Better, 2 = No change, going well, 3 = No change, not going well, 4 = Worse) for all eleven items. Total scores range from eleven to 44. The higher the score, the more severe the illness. Alpha reliability for the instrument in this study was .92.

Uncertainty. The 23-item Uncertainty in Illness Scale (Community version) (MUIS-C) is used by the individual who is not hospitalized and not likely to be receiving medical attention, or by family members of the person with chronic illness (See Appendix D).

Mishel (1981) developed the first form of the Mishel Uncertainty in Illness Scale (MUIS-A) in 1980. This first scale was developed to be used with ill, hospitalized adults. Instrument development began with an exploratory study of 45 hospitalized patients who were interviewed informally about their illness experience. From these interviews, a list of statements was developed and submitted to an expert group for evaluation. Statements were judged to reflect uncertainty if one of the eight uses of the term "uncertain" was present in the patient's statement (vague, ambiguous, inconsistent, lacking information, unpredictable, unclear, having multiple meanings, as a probability). Fifty-four statements resulted which were then worded "moderately positively or moderately negatively" (Mishel, 1981, pg. 259). The initial scale contained an equal number of moderately positive and moderately negative statements. Four factors were predicted: (1) ambiguity; (2) lack of information; (3) unpredictability; and (4) lack of clarity.

The 54-item scale was constructed on a five-point Likert scale format ranging from strongly disagree to strongly agree. The scale was reviewed by a group of nurses, doctors, and general medical/surgical patients to check for wording of questions. The scale was then administered to 259 hospitalized patients (134 medical, 51 rule-out diagnosis, 68 surgical, and 6 patients with missing data). Factor analysis indicated two factors: (1) multi-attributed ambiguity, defined as the "cues about the state of the illness are vague and indistinct and tend to blur and overlap" (23 items); and (2) unpredictability defined as the "lack of congruency between illness and treatment cues and illness outcomes" (4 items). Multi-attributed ambiguity had a standardized alpha of .91. Unpredictability had a standardized alpha of .64, which, according to Mishel (1981), was adequate for a four-item factor then but two items were added to improve the reliability in subsequent testing.

A replication of the two-factor solution was conducted with 100 patients from a medical service (Mishel, 1981). The pattern of loadings for this sample was similar to the original study. In the second population the reliability estimate for the ambiguity factor was .89 (standardized alpha) and .72 for unpredictability (standardized alpha) using the 6-item subscale.

Three validation studies were conducted on the initial MUIS-A instrument (Mishel, 1981). The purpose of the first validation study was to test the proposition that patients undergoing rule-out diagnostic procedures perceive more uncertainty than medical/surgical patients with established diagnoses. A one-way ANOVA of uncertainty scores by treatment group was conducted on the initial population of 259 patients. A significant treatment effect was found on both the multi-attributed ambiguity factor, F (2,250) = 19.88, $p < .001$; and the unpredictability factor, F (2,250) = 12.66, $p <. 001$. A series of *t* tests were computed for all pairs of treatment categories, and the rule-out group mean of 87.62 was significantly higher than both the surgical group mean of 65.64 and the medical group mean of 76.62. Findings from all population samples studied (medical, surgical, rule-out) indicated support for the construct validity of the scale.

The purpose of the second validation study was to confirm hypotheses about the relationship between perceived uncertainty and the degree of stress experienced by hospitalized patients. According to the Uncertainty in Illness theory, stress should occur when the patient is not able to cope with uncertainty (Mishel, 1981). The MUIS-A scale and the Hospital Stress Events Scale (Volicer, 1977) were administered to 100 medical patients. Results suggested that a patient's level of perceived uncertainty was strongly related to ratings of hospital stress events ($r = .35$, p<. 001). According to Mishel, the findings from this study provided support for the convergent validity of the scale.

The third validation study provided further support for the validity of the MUIS-A by converging the MUIS-A scale with the Comprehension Interview adapted from the Recall Test (Cassileth, Zupkis, Sutton-Smith, March, 1980). Based on the Uncertainty in Illness theory, it was hypothesized that uncertainty would be related to lack of comprehension. Twenty-six cancer patients were administered the MUIS-A and the Comprehension Interview on their first day of treatment. This study (Patterson, 1981) suggested a high level of uncertainty was correlated with a lower level of comprehension (r = -.56, p <. 002). Mishel interpreted the significant correlation between two different methods of measuring uncertainty as providing support for convergent validity (Mishel, 1997).

The original MUIS-A was re-analyzed in 1982 using the original data set, and a four-factor scale was devised with the subscales of ambiguity, complexity, lack of information, and unpredictability. As more data sets were obtained from researchers, concerns were raised about the reliability and validity of both the lack of information and unpredictability factors as the scale underwent multiple testing by various researchers. Based on these concerns, the 34 item four-factor version of the MUIS-A was re-factored in 1986 using a data set of 616 patients. A four-factor structure again emerged, however, lack of information and unpredictability continued to show inconsistent and variable reliabilities. Therefore a two-factor structure of 28 items was developed (ambiguity and complexity). This scale was found to be highly reliable and stable across various populations.

In 1989, Mishel attempted to replicate a four-factor structure with a data set of 1199 subjects. The four factors that emerged from the re-analysis were: (1) ambiguity- vague, indistinct, blurring, and overlapping cues about the illness; (2) complexity- multiple intricate, varied cues about the treatment and system of care; (3) inconsistency- receiving information that changes frequently or is not in accord with previously received information, and (4) unpredictability- lack of congruency between illness and treatment cues and illness outcome. Reliability of the four factors range from .71 to .91 and have been strongest for ambiguity and complexity (Mishel & Epstein, 1990). The total scale has a standardized alpha of .91 (Mishel, 1990).

Normative data are available for the four-factor scale. There were no differences in mean scores of uncertainty for gender and age. Uncertainty continues to differ by level of education; individuals with lower levels of education have higher levels of uncertainty.

The MUIS scales have demonstrated the ability to reflect differences among patient populations as well as between patients experiencing a sudden, new invasive procedure versus patients experiencing a familiar invasive procedure (Mishel, 1981). The uncertainty scales are sensitive to changes over time as was demonstrated by Warrington and Gottlieb's (1987) work, which suggests that uncertainty scores decreased over the time of hospitalization.

Following the development of the MUIS-A scale, Mishel developed three additional uncertainty scales: (1) the community form of the MUIS (MUIS-C) which is used by the individual or family member of chronically ill individuals who are not hospitalized and not likely to be receiving medical attention; (2) the Parents' Perception of Uncertainty in Illness (PPUS), which measures the parents' uncertainty experience concerning their child's illness; and (3) the PPUS-FM scale which is an altered form of the PPUS in which the word "child" is changed to spouse, friend, sister, etc. to evaluate the degree of uncertainty experienced by a wife, husband, or family member concerning an ill family member.

For this study, the MUIS-C, a 23-item instrument with a 5-point Likert scale (strongly agree to strongly disagree) was used. The MUIS-C contains the same items as the MUIS-A, except the items referring to treatment and communication with health care providers have been deleted. Reliabilities range from alpha levels of .74-.92. Reliability coefficients for different population subgroups suggest there are no differences in mean scores of uncertainty based on gender or age. Mean uncertainty scores are inversely related to education level. To calculate the total score, all items are summed. Scores for the total score can range from 23-115. Only a total score can be obtained for this form of the MUIS-C. Higher MUIS-C scores indicate higher uncertainty.

The MUIS-C has been used in a wide range of patient populations including patients with rheumatoid arthritis (Braden, 1990), myocardial infarctions (Christman, McConnell, Pfeiffer, Webster, Schmitt, & Ries, 1988), breast cancer (Hilton, 1989; Wong & Bramwell, 1992), gynecological cancer (Mishel & Sorenson, 1991; Mishel, Hostetter, King, & Graham, 1994), coronary artery bypass graft surgery (Redeker, 1992), chronic obstructive pulmonary disease (Small & Graydon, 1992), and multiple sclerosis (Wineman, Durand, & Steiner, 1994).

Normative data from twenty studies using the MUIS-C have been compiled (Mishel, 1997). The uncertainty scores for the 5-point Likert scale range from 23-115 with a midrange score of 69 (Mishel, 1997). Mean scores ranged from 33.7 to 85.5 (SD = 8.6 to 16.3) (Mishel, 1997). Reliabililities for the MUIS-C range from .74-.92 (Mishel, 1997). Reliability for mothers in this study was .91; reliability for spouse/partners was also .91.

Reliability coefficients for different population subgroups suggest there are no differences in mean scores of uncertainty based on gender or age. Mean uncertainty scores decrease with an increase in education level (Mishel, 1997).

Family Hardiness. The Family Hardiness Index (FHI) was developed to measure family hardiness as a stress resistance and adaptation resource in families (McCubbin, M.A., McCubbin, H.I. & Thompson, 1986; 1996) (See Appendix E). The authors used Kobasa's (1979a) work as a guide in developing the FHI. Based on factor analysis, the original instrument had four interrelated components: (1) *co-oriented commitment* which examined the family's ability to work together to manage difficulties; (2) the family's *confidence* in being able to handle problems; (3) emphasis on viewing hardships as *challenges* rather than burdens; and (4) a sense of internal *control* rather than being the victim of circumstances (external control). Concurrent validity was established with the earlier version of the FHI, consisting of the four subscales, showing family hardiness was positively correlated with criterion indices of Family Flexibility, Family Time and Routines, Family Satisfaction, Marital Satisfaction, and Community Satisfaction.

Later factor analysis results revealed three components of commitment, challenge, and control. These original three concepts were found to adequately explain the concept of family hardiness and are stronger psychometrically than the four-factor approach (McCubbin, M.A. et al., 1986; 1996).

Co-oriented commitment is an eight-item scale measuring the family's sense of internal strengths, dependability and ability to work together to solve problems. Challenge is a six-item scale measuring the family's efforts to be innovative, active and willing to learn. Control is a six-item scale measuring the family's sense of being in control of family life rather than being shaped by outside life events and circumstances. Scoring is obtained by summing the items in the scale. Negative items are reversed. The respondent notes the degree to which each statement describes the current family situation on a 0-3 scale. Family hardiness is measured by summing the values of the individual responses (False=0, Mostly False=1, Mostly True=2, and True=3); a higher score indicates higher levels of family hardiness. A total family hardiness score was used in this study. Test-retest reliability of the FHI has been established as .86. The overall internal reliability is .82 (Cronbach's alpha). Reliability for mothers in this study was .69. For spouse/partners, reliability in this study was .68.

Initially the FHI was used in a study of 304 nonclinical families to determine family hardiness over the family life cycle as part of the Family Stress Coping and Health Project at the University of Wisconsin-Madison. Family hardiness was at its lowest point at the Single and Couple stages of the life cycle and higher in other stages (Preschool and School Age, Adolescent and Launching, Empty Nest and Retirement) of the family life cycle. Since the original study, groups of researchers have used the FHI to study several outcomes in a variety of cancer patients, and to examine satisfaction with family functioning and family member depression. In these studies, family hardiness predicted positive psychosocial outcomes.

Psychological Wellbeing. Mother and spouse/partner's psychological wellbeing will be measured by Ryff's (1989) Wellbeing Scale (WBS) (See Appendix F). Ryff's integration of mental health, clinical, and life span theories points to multiple converging aspects of positive psychological functioning.

The WBS-short form consists of 42 items that measure six dimensions of wellbeing: (1) environmental mastery; (2) purpose in life; (3) self acceptance; (4) personal growth; (5) autonomy; and (6) positive relations with others (Ryff, 1989). According to Ryff, environmental *mastery* is the ability to utilize resources in the environment, to manage effectively activities in multiple realms, and to change or create new environments if necessary. The second dimension, having a *sense of purpose in life*, includes having goals, a sense of directedness, and a feeling that there is meaning in life. *Self-acceptance,* the third dimension, includes a positive attitude toward self, as well as an acceptance of one's good and bad qualities and an acceptance of one's past life. The fourth dimension, *personal growth,* requires continued development of one's potential, to grow and expand as a person. *Autonomy,* the fifth dimension, is defined as self-determination, independence, and the regulation of behavior from within. The last dimension, *positive relations with others*, is defined as the ability to establish warm, satisfying, trusting relationships with others.

Each of these dimensions is incorporated into a subscale of 7 items and consists of items, such as "I am quite good at managing the many responsibilities of my daily life" (environmental mastery scale). A six point Likert scale ranging from 1(strongly disagree) to 6 (strongly agree) is used. When scoring the measure, responses on negatively worded items are reversed so that high scores reflect higher levels of wellbeing on each of the subscale dimensions. To assess psychological wellbeing in this study, subscale ratings were summed into an overall score of psychological wellbeing.

After using the original long form scale (84 items) on a sample of 321 young, middle aged and older adults, Ryff (1989) found that alpha coefficients of all 6 subscales ranged between .83 to .91. The test-retest reliability for all six subscales, over a six-week period, ranged from .81 to .88. Convergent and discriminant validity have been demonstrated with other measures of positive functioning (e.g., life satisfaction, affect balance, self-esteem, internal control, and morale) (r = .25 to .73) and negative functioning with measures of depression and external control (e.g., chance, powerful others, and depression subscales) (r = -.30 to -.60). Recent data from a national probability sample (Ryff, 1995) supported, via confirmatory factor analyses, the hypothesized six-factor structure (Ryff, 1996). In this study, alpha reliabilities for mothers was .82 and for spouse/partners was .80.

Mother's and Spouse/partners responses to open-ended questions about life with chronic illness. Mothers and spouse/partners were asked to respond to three open-ended questions asking how they deal with the uncertainty of chronic illness and what advice they have for other families living with a mother with chronic illness (See Appendix G). Mothers and spouse/partners were asked to respond to three questions: (1) How have you dealt with the uncertainty of chronic illness; (2) What advice do you have for other mothers with chronic illness and their spouse/partners; and (3) Is there anything else you would like to tell us about living with chronic illness? Responses to these questions were analyzed by two doctorally prepared faculty using content analysis procedures. Data was analyzed individually and differences regarding themes was resolved through discussion. An independent group of twelve graduate nursing students and one doctorally prepared faculty identified similar themes.

Table 5

Study Variables and Measures

Study Variables	Level of Measures	Measures	Reliability
Family Demographics			
Mothers' and Spouse/Partners'	Individual/Family	Family Demographic Profile	N/A
Mothers' Illness Demographics			
Mothers' Illness Information	Individual	Mothers' Illness Information Questionnaire	N/A
Severity of Illness			
Mothers' Severity of Illness	Individual	Life with Chronic Illness Questionnaire	.92 Mother
Uncertainty			
Mother and Spouse/Partner Uncertainty Levels	Individual	Uncertainty in Illness Questionnaire	.91 Mother .91 Spouse/ partner
Family Hardiness			
Mother and Spouse/Partner Family Hardiness Levels	Family*	The Family Hardiness Index	.69 Mother .68 Spouse/ partner
Outcome Measure			
Mother and Spouse/Partner Psychological Wellbeing Levels	Individual	Psychological Wellbeing Scale	.82 Mother .80 Spouse/ partner

*Family level variables, but measured as individuals' perception of this family system variable.

Procedure. Eligible families were introduced to the possibility of study participation by the nurse liaison from the participating clinics and support groups or the nurse researcher. After potential participants gave permission to be contacted, mothers were asked to complete the following instruments: (1) Family Demographics; (2) Mothers' Illness Information; (3) Life with Chronic Illness; (4) Uncertainty in Illness; (5) Family Hardiness Index; (6) Psychological Wellbeing Scale; and (7) Open-ended questions about life with chronic illness. Spouse/partners were asked to complete the following instruments: (1) Family Demographics; (2) Uncertainty in Illness; (3) Family Hardiness Index; (4) Psychological Wellbeing Scale; and (5) Open-ended questions about life with chronic illness. Once families consented to participate, a study introduction letter (See Appendix H), consent forms (See Appendix I), questionnaires, and a stamped return envelope were given to the family. Mothers and spouse/partners were instructed to complete questionnaires independently. Single mothers were included in the study sample. One week after receiving the questionnaires, the nurse researcher made a follow-up telephone call to the family to answer questions about the study and to encourage return of consent form and questionnaires (by mail) if participating. Each mother and father who participated in the study received $10.00 ($20.00 if both participated) as recognition of their time and effort upon completing and returning the questionnaires.

Human Subjects. Human subject approval was obtained from the Institutional Review Board of the University of Wisconsin-Madison Center for Health Sciences prior to beginning the study (See Appendix J).

Data Analysis. Data analysis was conducted using the Statistical Package for the Social Sciences (SPSS) (1993). Descriptive statistics were first calculated for the major study variables (uncertainty, family hardiness, psychological wellbeing), as well as for the demographic and illness variables. Correlational analyses were conducted to determine inter-correlations between all study variables including the demographic and illness variables.

Multiple regression was used to test for the ability of uncertainty and family hardiness to predict wellbeing and for the moderating (interaction) of uncertainty and family hardiness on psychological wellbeing. Separate regression models for mothers and spouse/partners were used. Also using separate models, congruency scores were used to test for congruence of mothers and spouse/partners on uncertainty and family hardiness and these congruence scores were used to see if they were significant predictors of psychological wellbeing. Obtaining congruency scores involved dividing the sample into a median split, creating congruence variables for both uncertainty and family hardiness and then using the congruence variables as predictors of psychological wellbeing. Alpha level was $p < .05$.

Content analysis was used to determine themes from the three open-ended questions.

Chapter V

Results

Findings from this study will be presented including correlations between demographic variables and all major study variables as well as results from hypotheses testing using multiple regression procedures. Lastly, results of the content analyses will be presented.

In this sample of 60 families of mothers with chronic illness, the mean of the 60 mothers' uncertainty in illness score was 59.35 (SD = 14.31) with a range of 31-87 (See Table 6). The mean of the 30 spouse/partners' uncertainty in illness score was 65.77 (SD = 13.76) with a range of 37-94 (See Table 6). The possible range of scores was 23 to 115 with a midpoint score of 69 (Mishel, 1997). Higher scores indicate higher levels of uncertainty. In a sample of eighteen prior studies, mean uncertainty scores ranged from 42.4 to 85.5 (Mishel, 1997). Uncertainty scores in this study were within the range of means (42.5 – 85.5) found in previous studies.

The mean of family hardiness score for mothers in this study was 33.32 (SD = 4.32) with a range of 25-48 and the mean of the spouse/partners' family hardiness score was 31.97 (SD = 4.25) with a range of 24-43 (See Table 6). The possible range of scores was 0 to 60 with higher scores indicating higher levels of family hardiness. Comparing prior research data from 304 families on family hardiness provided a mean family hardiness score of 47.39 (McCubbin, H. I. et al., 1996). Mothers and spouse/partners in this study had lower mean family hardiness scores than prior research indicating lower levels of family hardiness in these families.

In this study, the mean of mothers' psychological wellbeing score was 150.73 (SD = 9.57) with a range of 130-175; and the mean of 29 of the 30 spouse/partners' psychological wellbeing was 149.52 (SD = 17.30) with a range of 71-166 (See Table 6). The possible range of scores was 42 to 252 with higher scores indicating higher levels of psychological wellbeing. Means for psychological wellbeing in prior research ranged from 142.98 to 204.58 (Ryff, 1996). Mothers and spouse/partners psychological wellbeing scores in this study were within the means of psychological wellbeing scores in prior research. One spouse/partner did not return the Psychological Wellbeing questionnaire.

The Life with Chronic Illness scale was developed for this study, thus there is no other data for comparison. The mean score on the Life with Chronic Illness Scale of 59 of the 60 mothers' with chronic illness was 25.10 (SD = 6.25) with a range of 12 - 41. The possible range of scores was 11 to 44 with a higher score indicating higher levels of severity of illness. One mother did not return the Life with Chronic Illness questionnaire.

Table 6

Descriptive Statistics for Study Variables

Study Variables	Mean	SD	Sample Range	Possible Range
Mothers (N = 60)				
Uncertainty in Illness	59.35	14.31	31-87	23-115
Family Hardiness	33.32	4.32	25-48	0-60
Psychological Wellbeing	150.73	9.57	130-175	42-252
Life with Chronic Illness* (Severity of Illness)	25.10	6.25	12-41	11-44
Spouse/Partners (N = 30)				
Uncertainty in Illness	65.77	13.76	37-94	23-115
Family Hardiness	31.97	4.25	24-43	0-60
Psychological Wellbeing**	149.52	17.30	71-166	42-252

*Only mothers completed this instrument
**N varies due to missing data

Correlations Between Demographic Variables, Severity of Illness, Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness

Mothers Data

Severity of Illness

For mothers, total number of children was positively correlated with mother's severity of illness ($r = .31$, $p < .05$)(See Table 7), indicating mothers reporting higher illness severity had more children.

Uncertainty in Illness

The length of the mothers' present relationship was positively correlated with mothers' uncertainty ($r = .38$, $p < .05$) (See Table 7) so mothers who had been in a longer relationship with their spouse/partner reported higher uncertainty. In addition, the number of children from a prior marriage/relationship was positively correlated with uncertainty in illness ($r = .28$, $p < .05$), indicating that mothers who had children from a prior marriage or relationship reported higher levels of uncertainty (See Table 7).

Contrary to the investigators expectations, education and years of education were not negatively correlated with uncertainty for mothers with chronic illness.

Family Hardiness

There were no correlations between demographic variables and family hardiness for mothers with chronic illness.

Psychological Wellbeing

The number of children by a prior marriage was positively correlated with mothers psychological wellbeing ($r = .29$, $p < .05$) indicating mothers with children from prior marriages had higher levels of psychological wellbeing (See Table 7). In addition, having children living at home ($r = .39$, $p < .01$) as well as total number of children was positively correlated with mothers' psychological wellbeing ($r = .36$, $p < .01$)(See Table 7). The number of relatives living in the home was positively related to mothers' psychological wellbeing ($r = .34$, $p < .01$), however, the number of families with relatives living at home in this study was small ($n = 5$).

Finally, family income was negatively correlated with mothers psychological wellbeing ($r = -.26$, $p < .05$) indicating mothers with less family income had higher levels of psychological wellbeing (See Table 7).

Table 7

Correlations Between Demographic Variables, Severity of Illness, Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness (N = 60)

Study Variables	SI	UC	FH	PWB
Age	-.03	.15	.08	-.11
Years of education	.18	.07	.01	-.17
Highest degree obtained	.22	.01	.01	-.18
Occupation	-.06	.04	-.23	.12
Employment status	-.13	.10	.04	-.12
Race	.09	-.04	-.12	.14
Marital status	.22	.24	-.23	-.06
Length of present relationship	-.24	.38*	-.17	-.004
Number of children by present marriage	-.01	-.08	-.12	-.15
Number of children by prior marriage*	.20	.28*	.12	.29*
Total number of children	.31*	.23	.05	.36**
Age of children	-.17	.13	-.06	-.09
Gender of children	-.03	-.05	.20	-.14
Child living at home	.21	.22	.07	.39**
Number of relatives living in the home*	-.09	.12	.05	.34**
Family income	-.09	-.14	-.08	-.26*

*N varies due to missing data
SI = Severity of Illness

UC = Uncertainty in Illness Scale
FH = Family Hardiness Index
PWB = Psychological Wellbeing
*** p < .05 ** p < .01**

Correlations Between Illness Information, Severity of Illness, Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness

Mothers Data

Severity of Illness

For mothers, age at diagnosis was positively correlated with severity of illness ($r = .29$, $p < .05$) (See Table 8); mothers who were older at the time of diagnosis had higher illness severity.

The number of checkups for symptoms of chronic illness in the past year ($r = .33$, $p < .01$) as well as the total number of checkups ($r = .30$, $p < .05$) in the past year was positively correlated with severity of illness indicating the higher the number of checkups, the higher the level of severity of illness (See Table 8).

The number of times mothers were hospitalized for chronic illness ($r = .25$, $p < .05$), for reasons other than chronic illness ($r = .26$, $p < .05$) as well as the total number of hospitalizations in the past year ($r = .35$, $p < .01$) were positively correlated with severity of illness (See Table 8).

The use of therapies other than those listed on the questionnaire, were negatively correlated with severity of illness ($r = -.34$, $p < .01$) indicating the use of other complementary therapies was associated with lower levels of severity of illness (See Table 8).

Uncertainty in Illness

Mother's age at diagnosis was positively correlated with uncertainty in illness ($r = .52, p < .05$); mothers who were older at the time of diagnosis had higher levels of uncertainty about their illness (See Table 8).

The number of times mothers were hospitalized for their chronic illness in the past year was positively correlated with uncertainty in illness ($r = .37, p < 01$), indicating the higher the number of times mothers were hospitalized for their chronic illness, the higher their levels of uncertainty in illness (See Table 8).

Mothers' use of complementary therapies to manage chronic illness was positively correlated with uncertainty in illness ($r = .34, p < .01$) indicating mothers with higher levels of uncertainty were more likely to use complementary therapy to manage their chronic illness. Exercise was a complementary therapy positively correlated to uncertainty in illness, indicating mothers experiencing higher levels of uncertainty had higher levels of exercise used to manage chronic illness (See Table 8).

Family Hardiness

The number of visits for regular checkups in the past year was positively correlated with mothers' levels of family hardiness ($r = .30, p < .05$). The number of times mothers were hospitalized for chronic illness in the past year was negatively correlated with family hardiness ($r = -.32, p < .05$) indicating the higher number of times mothers were hospitalized for chronic illness, the lower the level of family hardiness (See Table 8).

Use of complementary therapy to manage chronic illness was negatively correlated with levels of family hardiness for mothers (r = -.30, p < .05); mothers with low levels of family hardiness had higher levels of complementary therapy use to manage chronic illness (See Table 8).

Psychological Wellbeing

The number of times mothers were hospitalized for reasons other than chronic illness in the past year was positively correlated with psychological wellbeing (r = .29, p < .05) indicating the higher the number of times mothers were hospitalized for reasons other than chronic illness, the higher their levels of psychological wellbeing (See Table 8).

For mothers, massage (r = .32, p < .05) and exercise (r = .27, p < .05) were positively correlated with psychological wellbeing. In addition, total number of complementary therapies was negatively correlated with psychological wellbeing (r = -.26, p < .05) indicating mothers with higher levels of psychological wellbeing were using fewer numbers of complementary therapies to manage their chronic illness (See Table 8).

Table 8

Correlations Between Illness Information, Severity of Illness, Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness (N = 60)

Study Variables	SI	UC	FH	PWB
First started having symptoms	-.04	.15	.18	.05
Age at diagnosis	.29*	.52*	-.21	-.12
Number of visits for regular checkups in the past year	.05	-.13	.30*	.09
Number of checkups for symptoms in the past year	.33**	.17	-.07	.10
Total number of checkups in past year	.30*	.10	.04	.12
Number of times hospitalized for chronic illness in the past year	.25*	.37**	-.32*	-.02
Number of times hospitalized for reasons other than chronic illness in the past year	.26*	-.02	.15	.29*
Total hospitalizations in past year	.35**	.23	-.10	.19
Number of prescription medications used to manage chronic illness	-.08	.15	-.09	.05
Number of over the counter meds used to manage chronic illness	-.11	.13	.21	.10
Total number of medications	-.11	.17	.02	.09
Use of complementary therapies to manage chronic illness	-.01	.34**	-.30*	-.02

Study Variables	SI	UC	FH	PWB
Vitamins/nutritional therapy	-.08	.25	-.11	.07
Herbal therapy	-.03	.02	.08	.23
Mind/body work	-.10	.02	.02	.17
Acupuncture	-.15	-.16	-.10	-.03
Acupressure	-.15	.05	-.11	.11
Massage	-.20	-.05	.03	.32*
Aromatherapy	-.14	-.02	.04	.001
Chiropractor	-.11	-.12	.007	-.09
Exercise	.23	.29*	-.10	.27*
Spiritual care	-.17	-.04	.06	.07
Use of other therapy	-.34**	.08	.18	.07
Total number of complementary therapies	.24	-.06	.01	-.26*

*N varies due to missing data
SI = Severity of Illness Scale
UC = Uncertainty in Illness Scale
FH = Family Hardiness Index
PWB = Psychological Wellbeing Scale
$* p < .05$ $** p < .01$ $*** p < .001$

Correlations Between Demographic Variables, Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Spouse/Partners of Mothers with Chronic Illness

Spouse/Partner Data

Uncertainty in Illness

The number of children living at home was positively correlated with levels of uncertainty in illness ($r = .52$, $p < .01$) for spouse/partners. In addition, the number of children from the present marriage ($r = .40$, $p < .05$) and the total number of children ($r = .43$, $p < .05$) were positively correlated with levels of uncertainty in illness (See Table 9). Thus, spouse/partners with more children (living at home, from present marriage and total number of children) reported higher uncertainty in mother's illness.

Spouse/partners uncertainty in illness was positively correlated with mothers severity of illness ($r = .50$, $p < .01$), suggesting the more severe the mothers illness, the higher the uncertainty for spouse/partners.

Family Hardiness

There were no correlations between the demographic variables and family hardiness for the spouse/partner of mothers living with chronic illness.

Psychological Wellbeing

For the spouse/partner, the number of years of education ($r = .40$, $p < .05$) and highest degree obtained ($r = .55$, $p < .01$) were positively correlated with spouse/partners psychological wellbeing ($r = .40$, $p < .05$), indicating spouse/partners with more years of education or higher degrees reported higher levels of psychological wellbeing (See Table 9).

Table 9

Correlations Between Demographic Variables, Uncertainty in Illness, Family Hardiness, and Psychological Wellbeing for Spouse/Partners of Mothers with Chronic Illness (N = 30)

Study Variables	UC	FH	PWB
Age	.28	-.17	.10
Years of education	.20	-.06	.40*
Highest degree attained	.17	-.04	.55**
Occupation	-.14	.24	-.01
Employment status	.18	.02	-.01
Race	a	a	a
Marital status	.10	.02	-.06
Length of present relationship	.24	-.15	-.05
Number of children from present marriage	.40*	.02	-.26
Number of children from prior marriage	.16	-.08	.14
Total number of children	.43*	-.29	-.32
Age of children	.25	-.25	-.14
Gender of children	.16	.05	.18
Child living at home	.52**	.13	.26

Study Variables	UC	FH	PWB
Number of relatives living in the home	a	a	a
Family income	.20	.02	-.01

a = cannot be computed because at least one of the variables is constant

UC = Uncertainty in Illness Scale
FH = Family Hardiness Index
PWB = Psychological Wellbeing Scale
* p < .05 ** p < .01 *** p < .001

Correlations between Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness and their Spouse/partner

Mothers Data

For mothers, there was a trend for uncertainty in illness being positively correlated with mothers' psychological wellbeing (r = .24, p = .06). In addition, mothers' family hardiness was positively correlated with mothers' psychological wellbeing (r = .35, p < .01) (See Table 10); therefore, higher family hardiness was associated with higher psychological wellbeing for mothers.

Spouse/partners Data

For spouse/partners, there was a trend for family hardiness being positively correlated with their psychological wellbeing (r = .33, p = .07) (See Table 10).

Study Variable Correlations between Mothers and their Spouse/partner

Mothers' uncertainty in illness was positively correlated with spouse/partners uncertainty in illness (r = .49, p < .01). Mothers' family hardiness was positively correlated with spouse/partners' psychological wellbeing (r = .56, p < .01). In addition, the relationship between mothers' and spouse/partners' family hardiness approached significance (r = .34, p = .06) (See Table 10).

Table 10

Correlations between Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness (N = 60) and their Spouse/partner (N = 30)

Study Variables	Mothers SI	Mothers UC	Mothers FH	Mothers PWB	Spouse/ partners UC	Spouse/ partners FH	Spouse/ partners PWB*
Mothers SI	_____	.18	.02	.06	.50**	-.22	.32
Mothers UC		_____	-.18	.24†	.49**	-.07	.01
Mothers FH			_____	.35**	.19	.34†	.56**
Mothers PWB				_____	.09	.21	.12
Spouse/ partners UC					_____	-.25	.24
Spouse/ partners FH						_____	.33†
Spouse/ partners PWB*							_____

*N varies due to missing data
SI = Severity of Illness
UC = Uncertainty in Illness
FH = Family Hardiness
PWB = Psychological Wellbeing
†p < .10 * p < .05 ** p < .01 *** p < .001

Hypothesis Two: Uncertainty will be a significant negative predictor of psychological wellbeing for mothers and their spouse/partner.

For mothers, demographic variables (total number of children and family income) accounted for 21.2% of the variance in mothers' psychological wellbeing with uncertainty adding another 1.5% for a total of 22.7% of the variance in psychological wellbeing. Uncertainty was not a significant predictor of psychological wellbeing for mothers ($\beta = .13$, $p = .309$) (See Table 12).

For spouse/partners, the demographic variable (years of education) accounted for 16.0% of the variance in spouse/partners' psychological wellbeing with uncertainty adding another 2.7% for a total of 18.7% of the variance in psychological wellbeing. Uncertainty was not a significant predictor of psychological wellbeing for spouse/partners ($\beta = .17$, $p = .352$) (See Table 12).

In this study, uncertainty was not a significant negative predictor of psychological wellbeing for mothers or spouse/partners (See Table 12). This was contrary to the investigators hypothesis where uncertainty was expected to be a significant negative predictor of psychological wellbeing. Thus, this hypothesis was not supported for mothers or spouse/partners.

Table 12

Hierarchical Regression Model for Uncertainty as a Predictor of Psychological Wellbeing in Mothers with Chronic Illness (N = 60) and their Spouse/partner (N = 30)

Predictor Variable	B	SE B	β	R	R^2	F
Mothers (N = 60)						
Step 1						
Total # children	.86	.30	.35			
Family income	-.897	.36	-.29**	.461	.212	7.69***
Step 2						
Uncertainty in Illness	8.403	.08	.13	.476	.227	5.482**
Spouse/partners (N = 30)						
Step 1						
Years of education	3.248	1.408	.367*	.400	.160	5.319*
Step 2						
Uncertainty in Illness	.21	.22	.17	.43	.187	3.098

* $p < .05$

** $p < .01$

*** $p < .001$

Hypothesis Three: Family hardiness will be a significant positive predictor of psychological wellbeing for mothers and their spouse/partner.

The significant demographic variables (total number of children and family income) for mothers accounted for 21.2% of the variance in mothers' psychological wellbeing with family hardiness adding another 9.8% for a total of 31% of the variance in psychological wellbeing. Family hardiness was a significant predictor of psychological wellbeing for mothers ($\beta = .32$, $p = .007$) (See Table 13).

The significant demographic variable (total years of education) for spouse/partners accounted for 16% of the variance in spouse/partners' psychological wellbeing with family hardiness adding another 12.4% for a total of 28.4% of the variance in psychological wellbeing. In this study, family hardiness did significantly predict psychological wellbeing for spouse/partners ($\beta = .35$, $p = .04$) (See Table 13).

For mothers and spouse/partners, family hardiness was a significant positive predictor of psychological wellbeing; thus, this hypothesis was supported.

Hypothesis Four: Family hardiness will function as a moderator between uncertainty and psychological wellbeing for mothers and their spouse/partner.

Significant demographic variables for mothers accounted for 21.2% of the variance in mothers' psychological wellbeing (ß = .29, p = .02). Uncertainty added an additional 1.5% (ß = .13, p = .31) and family hardiness an additional 12% (ß = .36, p = .002) with the interaction term not adding any additional variance in psychological wellbeing for mothers. For mothers, 34.7% of the variance in psychological wellbeing was explained with the demographic variables and family hardiness being significant; however, uncertainty and the moderating interaction term were not significant (See Table 14).

For spouse/partners, the significant demographic variables (years of education) accounted for 16% of the variance in psychological wellbeing (ß = .40, p = .03). Uncertainty added an additional 2.7% (ß = .17, p = .35) and family hardiness an additional 16.3% (ß = .42, p = .02) with the interaction term not adding any additional variance in psychological wellbeing for spouse/partners. For spouse/partners, 35.1% of the variance in psychological wellbeing was explained with the demographic variables and family hardiness being significant; however, uncertainty and the moderating interaction term were not significant (See Table 15).

Family hardiness did not function as a moderator between uncertainty and psychological wellbeing for mothers or their spouse/partners; thus, this hypothesis for not supported for mothers or spouse/partners.

Table 13

Hierarchical Regression Model for Family Hardiness as a Predictor of Psychological Wellbeing in Mothers with Chronic Illness (N = 60) and their Spouse/partner (N = 30)

Predictor Variable	B	SE B	β	R	R^2	F
Mothers (N = 60)						
Step 1						
Total # children	.86	.30	.35**			
Family income	-.897	.36	-.29*	.461	.212	7.69*
Step 2						
Family Hardiness	.70	.25	.32**	.557	.310	8.406**
Spouse/partners (N = 30)						
Step 1						
Years of education	3.248	1.408	.367*	.400	.160	5.319*
Step 2						
Family Hardiness	1.41	.65	.35*	.53	.284	4.709*

* $p < .05$

** $p < .01$

*** $p < .001$

Table 14

Hierarchical Regression Moderation Models for Predicting Psychological Wellbeing in Mothers with Chronic Illness (N = 60)

Predictor Variables	B	SE B	β	R	R²	F
Mothers (N = 60)						
Step 1						
Total # children	.86	.30	.35			
Family income	-.897	.36	-.29***	.461	.212	7.69***
Step 2						
Uncertainty in Illness	8.403	.08	.13	.48	.227	1.055
Step 3						
Family Hardiness	.80	.25	.36	.59	.347	10.124**
Step 4						
Interactions						
UC x FH	-1.325	.02	-.06	.59	.347	.006

* p < .05

** p < .01

*** p < .001

UC = Uncertainty in Illness

FH = Family Hardiness

Table 15

Hierarchical Regression Moderation Models for Predicting Psychological Wellbeing in Spouse/partners of Mothers with Chronic Illness (N = 30)

Predictor Variables	B	SE B	β	R	R^2	F
Spouse/partners (N = 30)						
Step 1						
Total years of education	3.248	1.408	.40*	.40	.160	5.319*
Step 2						
Uncertainty in Illness	.20	.22	.17	.43	.187	.897
Step 3						
Family Hardiness	1.668	.65	.42*	.59	.350	6.552*
Step 4						
Interactions						
UC x FH	-5.976	.06	-.16	.59	.350	.012

* $p < .05$

** $p = .01$

*** $p = .001$

UC = Uncertainty in Illness

FH = Family Hardiness

Table 16

Hierarchical Regression Model for Congruency between Mothers with Chronic Illness (N = 30) and their Spouse/partner (N = 30) for Uncertainty Predicting Psychological Wellbeing

Predictor Variable	B	SE B	β	R	R^2	F
Mothers Psychological Wellbeing (N = 30)						
Step 1						
Total # children	.37	.61	.12			
Family Income	-.77	.75	-.20	.21	.043	.610*
Step 2						
UC Congruency	-.95	2.084	-.10	.23	.051	.206
Spouse/partners Psychological Wellbeing (N = 30)						
Step 1						
Years of education	3.248	1.408	.367*	.400	.160	5.319*
Step 2						
UC Congruency	4.311	3.229	.23	.46	.212	1.782

* p < .05

** p < .01

*** p < .001

UC = Uncertainty in Illness

Table 17

Hierarchical Regression Model for Congruency between Mothers with Chronic Illness (N = 30) and their Spouse/partner (N = 30) for Family Hardiness Predicting Psychological Wellbeing

Predictor Variable	B	SE B	β	R	R^2	F
Mothers Psychological Wellbeing (N = 30)						
Step 1						
Total # children	.37	.61	.12			
Family Income	-.77	.75	-.20	.21	.043	.610*
Step 2						
FH Congruency	-2.357	1.870	-.24	.31	.098	1.589
Spouse/partners Psychological Wellbeing (N = 30)						
Step 1						
Years of education	3.248	1.408	.367*	.400	.160	5.319*
Step 2						
FH Congruency	-2.962	3.647	-.15	.42	.180	.660

* $p < .05$

** $p < .01$

*** $p < .001$

FH = Family Hardiness

CONTENT ANALYSIS:

The final purpose of this study was to examine mothers' and spouse/partners' responses to three open ended questions asking how they deal with the uncertainty of chronic illness and what advice they have for other families living with a mother with chronic illness. Mothers and spouse/partners were asked the following questions: (1) How have you dealt with the uncertainty of chronic illness; (2) What advice do you have for other mothers with chronic illness and their spouse/partners; and (3) Is there anything else you would like to tell us about living with chronic illness? Answers to these three questions were analyzed by two doctorally prepared faculty who identified themes from the mother's and spouse/partner's responses. An independent group of twelve graduate nursing students and one doctorally prepared faculty identified similar themes following their content analysis of mothers and spouse/partners responses.

Four general themes were identified from mothers and spouse/partners responses to questions about living with chronic illness: (1) *Education,* which included educating friends and other family members about the illness, including the impact of the illness on the family, was important to mothers and their spouse/partners; (2) *Seeking support* which included asking others for help and seeking emotional support from others; (3) *Creative problem solving* which included setting priorities and simplifying their lives; and (4) *Living for today* included living day by day and planning activities at the last minute rather than far ahead when the illness may prevent following through with planned activities.

Research Question One: How have you dealt with the uncertainty of chronic illness?

Education about the illness, as a way to deal with the uncertainty of chronic illness, was an important strategy for mothers and their spouse/partners. Learning about the illness included learning about the disease itself as well as learning what brings on episodes of chronic illness. Mothers and spouse/partners wanted to learn about the disease in order to learn how to control or manage symptoms in order to live a "normal" life.

Mothers:

> "I try to learn what brings on episodes and control it (the chronic illness)."
>
> "By NOT ignoring it, getting knowledge and doing what I can to help things work for the better."
>
> "I have decided to control it and NOT let it control me."
>
> "I haven't learned yet how to equalize the bad pain and medium pain days. There are very few good days with little pain. Once I can learn the triggers and how to cope with them I think we will all do better."

Spouse/partner:

> "I have the most wonderful wife who controls her illness. In emergency cases I know what I need to do. I also encourage my wife and tell her what a good job she is doing."
>
> "It's complicated – the meds, accuchecks, etc. but she does a good job. I help when I can."

Learning about the illness helped mothers and spouse/partners know what to expect and helped them in maintaining a sense of "normalcy" in their families' lives. One mother stated:

Despite educating themselves about the illness and using creative problem solving, mothers and spouse/partners also discussed the frustrations they felt in trying to deal with the uncertainty of chronic illness.

Mothers:

> "My family is trying to accept and deal with this but has trouble since they can't see the pain and numbness. They see me trying to have a good day and then treat me as if the illness is gone. They get frustrated that I need to slow things down or that I'm limited with some activities. Basically, they want it to go away too."

> "I work out…try to take care of myself but then am disappointed when my blood sugars are still high. It's very frustrating. I have a hard time with this."

> "Take one day at a time. I get depressed and cry. I read and research. I hope every day I find that positive attitude to pull that foot out of the grave."

> "I never realized how much my self-esteem would be affected by not being able to work and do the things I used to. I feel like I can't plan much because I have no idea if I'll improve, get worse or better."

Spouse/partner:

> "It's been difficult to cope since I'm a person on the go and with two young children and a wife with chronic illness, that creates some friction. The disease is "shrouded in mystery" so it's hard to be genuinely empathetic."

> "This disease is hard to deal with because you can't "see" it. I know my wife is tired but it's frustrating."

Research Question Two: What advice do you have for other mothers with chronic illness and their spouse/partners?

Educating yourself about the illness was again mentioned as being an important aspect of living with chronic illness. Mothers and their spouse/partners suggested that learning about the chronic illness was helpful in managing their disease as well as educating others about the symptoms of the disease. Educating others included teaching children in the family about the illness and keeping them informed throughout the course of the illness.

Mothers:

> "Meet with the family and explain the different issues involved. My son (9 years old) had lots of questions. I don't have all the answers for all of them but promised to keep him informed when I got the answers."
>
> "Never give up! If you enjoy life and want to keep living life you must stay on top of your illness. Don't be afraid to talk about it. The more educated people can be, the better off every one will be."

Spouse/partner:

> "Help educate each other about the illness and also educate children who are old enough to understand so they aren't in the dark on why mom is feeling this way."

Seeking support was identified by mothers and their spouse/partners as being an important aspect of living with chronic illness. Mothers and their spouse/partners suggested families ask for help from others in dealing with chronic illness. "Help from others" included help from other family members as well as support groups and others with chronic illness. Mothers suggested joining support groups in order to meet and talk with others going through similar experiences as themselves.

Mothers:

> "Don't feel guilty about asking for help or reorganizing family chores (this is a hard one, especially if you are used to being full of energy and able to "do it all."
>
> "Ask for help and explain why you need the help. Join support groups to talk with others going through what you are going through."
>
> "No matter how much you love your kids, sometimes you can't handle it well alone. I chose to enroll my two year old in daycare. He'll get a lot of physical activity and it saves me from running after him those mornings."
>
> "If you have pain, ask for help. When you feel better, offer help to others who need it."

Spouse/partners:

> "Work together to make life as good as possible for the entire family."
>
> "Be honest with each other, especially about limitations and expectations."

Lastly, *living for today* was advice mothers and their spouse/partners gave to others living with chronic illness. Living for today included trying to live day by day and planning activities at the last minute in an effort to live with the unpredictability of chronic illness.

Mothers:

> "I learned to let go of the little things (I'm still working on this). You have to choose priorities differently, for example, you can't have a perfect house and get everything else done so I pick... my house will be organized and clean but not dusted as well."

Spouse/partner:

> "...get rest, good nutrition, and simplify your life and home to overcome obstacles."

Mothers and spouse/partners also identified a number of frustrations they have experienced in trying to live with chronic illness.

Mothers:

> "Don't feel guilty about asking for help or reorganizing family chores (this is a hard one, especially if you are use to being full of energy and able to "do it all")."
>
> "Living with a chronic illness is a challenge and struggle everyday. I think I take better care of myself now than before I had a family- I know and want to be healthy for my family because I want to be around and watch my family grow. They need me- You can't do everything alone- your spouse needs to help out because you have so many extra things to do just in controlling your disease."

Spouse/partners:

> "Try to be understanding…it's hard because this illness is so unpredictable."

Mothers and spouse/partners offered suggestions on how to deal with these frustrations which included communicating to others when they needed help or support, using creative problem solving strategies in order to manage the frustrations they were experiencing and living for today in order to not be disappointed when not able to meet long term goals (see prior quotes).

Research Question Three: Is there anything else you would like to tell us about living with chronic illness?

Mothers and their spouse/partners again mentioned the importance of learning about the disease process, asking for help and support, creative problem solving, and trying to live as "normal" a life as possible.

Both mothers and spouse/partners identified a positive attitude as being an important element of managing life with chronic illness.

Mothers:

> "It (chronic illness) affects everything in your life. Communication, patience, being open-minded and willing to change how to do things is necessary. I don't think you can get along without all of these things and even with all four, it is so hard. I don't like being put into this phase of my life and decided I'm not giving in. I can't make it go away but I will try everything I can to make the quality of my life better. It's hard on everyone in the family, especially spouses. Education about your illness is so important. Try to keep "fun" in your lives (which is very hard when you are in pain) even if it's in just little ways."

> "Be kind to yourself, be patient with yourself. There will be slip-ups, but get back up and back to work- caring for yourself. Be thankful- there are always worse things that can happen. Trying to be positive will always help you feel better."

> "You are going to have your ups and downs! Don't let it BEAT you- attitude is key and education about your illness too."

Spouse/partners:

> "We laugh about it sometimes- humor is as good a medicine as any. Don't let the illness stand in the way of a good upbringing for children."
>
> "Learn to balance life. My spouse has learned and changed to adapt to her illness. I could benefit to learn a lot from her."

Frustrations and anguish were expressed too in response to this question.

Mothers:

> "My 17 year old son does not accept and doubts my illness. I often get stressed out and hurt. Educating at teachable moments is better than when you're angry because he won't help or puts me down."
>
> "It rules what you do as a family- travel, family outings, etc. Try not to be as frustrated or down on yourself."
>
> "I have learned that I need to control so many things- when I eat, how and when I exercise, what meds I take, etc. etc. It is hard to be spontaneous, plus because I need to control all this, I feel like any negative outcomes will be because I don't do it well enough."
>
> "It's a silent illness- people think it's all in your head and it's SO frustrating! There needs to be more public awareness and more support for sufferers of fibromyalgia."
>
> "It's difficult living with chronic illness. Fatigue, headaches, cognitive problems."

Spouse/partners:

> "It's frustrating."
>
> "It's a pain in the neck not knowing what's going to happen down the road in years to come. It's like a silent death happening to your spouse."
>
> "Difficult being significant other and living with someone with fibromyalgia."

Chapter VI

Discussion

The purposes of this study were to: (1) describe levels of uncertainty, family hardiness, and psychological well-being in both mothers with a chronic illness and their spouse/partner; (2) test for direct and moderating effects of uncertainty and family hardiness on psychological well-being in mothers and their spouse/partner; (3) examine congruence between mothers' and spouse/partners' uncertainty and family hardiness and the relationship to their psychological well-being; and (4) examine mothers and spouse/partners responses to open ended questions asking how they deal with the uncertainty of chronic illness, what advice they have for other families living with a mother with chronic illness, and if there is anything else they would like to tell us about living with chronic illness.

Severity of Illness

For mothers, total number of children was positively correlated with mother's severity of illness, indicating mothers reporting higher illness severity had more children. In addition, age at diagnosis was positively correlated with severity of illness, indicating mothers who were older at the time of diagnosis had higher illness severity (See Table 8). A possible explanation for this finding could be that mothers who were older at the time of diagnosis had more advanced disease, thus higher illness severity. In addition, it is likely that as mothers age, the illness becomes more severe. Since mothers were older at diagnosis, they may have also had more children by the time of diagnosis. In addition, having more children may put more strain on mothers with chronic illness therefore increasing severity (i.e. mothers may require more medication, more checkups, more hospitalizations for chronic illness).

In the past year, the number of checkups for symptoms of chronic illness, the total number of checkups, the number of hospitalizations for chronic illness, the number of times mothers were hospitalized for reasons other than chronic illness, as well as the total number of hospitalizations, were all positively correlated with severity of illness, indicating mothers with higher levels of illness severity reported higher levels of health care seeking behaviors (See Table 8). In other words, mothers who were sicker were hospitalized more often and required more checkups than mothers with less severe illness.

In addition to seeking health care, mothers used complementary therapy to manage the symptoms of chronic illness. Mothers reported using complementary therapies (physical therapy, yoga, humor), which were not listed on the Mother's Illness Information questionnaire. These other therapies were negatively correlated with severity of illness indicating the use of these other therapies was associated with lower levels of illness severity (See Table 8). A possible explanation for this finding is that these mothers had found other complementary therapies (physical therapy, yoga, humor) as helpful in managing the symptoms of their chronic illness and, as a result, had lower levels of illness severity.

Mothers' severity of illness was positively correlated with spouse/partner's uncertainty, indicating spouse/partners reported higher levels of uncertainty associated with mothers' higher illness severity. A possible explanation for this finding could be that in more severe illness, spouse/partners are faced with more unpredictability and complexity surrounding the illness, which is associated with higher levels of uncertainty for spouse/partners (See Table 11).

Uncertainty

For mothers, age at diagnosis was positively correlated with uncertainty in illness; thus mothers who were older at the time of diagnosis had higher levels of uncertainty about their illness (See Table 8). Chronic illnesses that are gradual in onset and episodic in nature are more likely to be diagnosed at a more advanced stage. Thus, mothers may be older by the time of diagnosis. In addition, mothers may have faced delays in diagnosis (mean time from 1st symptom to diagnosis was 48.12 months), numerous possible diagnoses and experienced a variety of symptoms before receiving a definitive diagnosis and thus be older and have higher levels of uncertainty by the time they receive a diagnosis of chronic illness.

For mothers, the length of their present relationship was positively correlated with uncertainty in illness, indicating the longer the mother's present relationship the higher the level of uncertainty in illness (See Table 7). A possible explanation for this finding could be that the longer the mother's present relationship, the older the mother and the more symptoms she may have experienced, thus the greater the level of uncertainty about the disease.

The number of children by a prior marriage was positively correlated to uncertainty in illness for mothers (See Table 7). Mothers who have children by a prior marriage are more likely to be older, thus they may have experienced a variety of symptoms leading to higher levels of uncertainty about their disease. Older mothers are more likely to be in a relationship longer and may have more children from prior marriages.

In previous studies, frequency of hospitalizations was considered a measure of severity of illness and was positively correlated with uncertainty (Andersson-Stegesten, 1991; Ronayne, 1989; Van Den Borne, 1987; Webster & Christman, 1988). In this study, the number of times mothers were hospitalized for their chronic illness in the last 12 months was also positively correlated with uncertainty in illness, indicating the higher the number of times mothers were hospitalized the more severe their illness and the higher their level of uncertainty (See Table 8).

Numerous researchers have examined methods individuals use to manage the uncertainty of chronic illness. Braden (1992), in a study of 291 individuals with systemic lupus erythematosus, found that uncertainty and depression decreased over time when participants engaged in self help activities such as rest, relaxation, heat and exercise activities. In this study, there were a number of interesting findings related to complementary therapy use in mothers with chronic illness as a way to manage their chronic illness symptoms. Uncertainty was positively correlated with the use of complementary therapy (See Table 8). Mothers with higher levels of uncertainty were more likely to use complementary therapy to manage their chronic illness, possibly indicating that mothers reporting higher levels of uncertainty were more likely to try other types of treatment, including complementary therapy, with the hope of better control of their chronic illness. Use of complementary therapy may be a strategy mothers use to help control symptoms or manage the unpredictability of chronic illness. The use of exercise was positively correlated with uncertainty in illness suggesting mothers experiencing higher levels of uncertainty were using exercise as a form of complementary therapy.

For spouse/partners, the number of children living at home was positively correlated with uncertainty. In addition, the number of children from the present marriage and the total number of children were positively correlated with levels of uncertainty in spouse/partners (See Table 9). A possible explanation for this finding could be that for spouse/partners, more children living in

In this study, the number of visits for regular checkups in the last 12 months was positively correlated with family hardiness (See Table 8). Seeking preventative care may be one way mothers try to maintain a sense of control over their lives by taking personal responsibility for their own health care.

Mothers' hospitalizations for chronic illness in the past year were negatively correlated with mothers reports of family hardiness indicating more frequent hospitalizations were correlated with lower levels of family hardiness. Families experiencing frequent hospitalizations may feel a loss of control over their disease as well as a lack of ability to manage difficulties. They may also view any relapses of their chronic illness as a family hardship rather than a challenge.

The use of complementary therapy was negatively correlated with family hardiness for mothers with chronic illness indicating mothers reporting lower levels of family hardiness were using complementary therapy. Mothers may use complementary therapy as a way to manage or control the symptoms of their chronic illness, thus giving families more control over their chronic illness.

Psychological Wellbeing

Social support has been found to be a significant positive predictor of psychological wellbeing (Lambert et al., 1990). Previous studies have suggested having children living at home provides a source of support to mothers diagnosed with HIV (Jarret, 1996). In this study, mothers who had children living at home had higher levels of psychological wellbeing (See Table 8).

Mothers living with chronic illness often rely on other family members to assist with household chores and tasks, often children living in the household. For mothers, the total number of children, as well as the number of children from prior marriage/relationships, was positively correlated with psychological wellbeing, which may indicate the presence of children as providing a source of support for mothers with chronic illness. The presence of children from prior marriage/relationships may have been older in age and thus, possibly more help to mothers with chronic illness than younger children in the family.

The number of relatives living in the home was also positively correlated with mothers' psychological wellbeing, again suggesting having relatives living in the home as being a source of support for mothers living with chronic illness. This finding should be viewed with caution, however, as the number of relatives living in the home was small ($n = 5$).

One unexpected study result was that family income was negatively correlated with psychological wellbeing for mothers (See Table 8). A possible explanation could be that those mothers trying to manage life with chronic illness who either do not work outside the home or have part time employment have a lower family income but possibly higher psychological wellbeing since they do not have the stress of combining full time work, family responsibilities and management of their chronic illness. In this study, 33.9 % of mothers did not work or had part time employment.

For mothers, the number of times hospitalized for reasons other than chronic illness ($n = 11$) in the past year was positively correlated with mothers' psychological wellbeing. The majority of mothers in this study were of childbearing age; possibly indicating mothers were being hospitalized for childbirth rather than chronic illness. For mothers living with chronic illness, hospitalization for childbirth may be a joyful occasion as mothers may have had difficulty becoming pregnant due to their chronic illness thus the increase in mothers' psychological wellbeing. These findings should be viewed with caution, however, as only a small number of mothers had children under the age of one (n = 2).

Exercise and massage were positively correlated with psychological wellbeing for mothers in this study (See Table 8). This finding was supported in prior research (Braden, 1991). In addition, the total number of complementary therapies was negatively associated with psychological wellbeing for mothers (See Table 8), possibly indicating that mothers with low levels of psychological wellbeing were trying numerous complementary therapies in an effort to manage the symptoms of their disease. Mothers with high levels of psychological wellbeing were using a smaller total number of complementary therapies, possibly finding one or two therapies that tended to work well for them, thus eliminating the need for numerous forms of complementary therapy to manage their illness.

For the spouse/partner, the number of years of education and the highest degree obtained were positively correlated with psychological wellbeing (See Table 9). This supports Ryff's (1989) previous finding comparing years of education and psychological wellbeing.

Correlations Between Uncertainty in Illness, Family Hardiness and Psychological Wellbeing for Mothers with Chronic Illness and their Spouse/partner

Mothers' family hardiness was positively correlated with mothers' psychological wellbeing (r = .35, p < .01) (See Table 10). In addition, there was a trend for spouse/partners family hardiness to be positively correlated with spouse/partners' psychological wellbeing (r = .33, p = .07) (See Table 10). This finding supports prior research in which family hardiness was positively correlated with wellbeing (Svavarsdottir et al., 2000; McCubbin, H. I., 1989; and McCubbin, H. I. & Thompson, 1992).

Family hardiness refers to the internal strengths and durability of the family unit and is considered a stress resistance and adaptation resource in families. Family hardiness functions as a buffer in mitigating the effects of stressors and demands and a facilitator of family resiliency adjustment and adaptation over time. Family hardiness may offset the illness producing effects of stress on individuals and thus may be associated with higher levels of psychological wellbeing.

Correlations between Mothers and their Spouse/partner Data

Mothers' uncertainty in illness was positively correlated with spouse/partners uncertainty in illness (r = .49, p < .01). Mother and spouse/partners congruency of levels of uncertainty is important for families living with chronic illness. Mishel (1999) suggests, for the well spouse, congruence between each spouse's positive perception of uncertainty was critical in determining the well spouse's positive family satisfaction. Spouses where incongruence existed had lower levels of family satisfaction.

In addition, mothers' family hardiness approached significance with spouse/partners' family hardiness (r = .34, p = .06) (See Table 10). Family hardiness refers to the internal strengths and durability of the family unit and is characterized by a sense of control over outcomes of life, a view of change as growth producing, and an active rather than a passive orientation in adapting to stressful situations (McCubbin, H.I. et al., 1996). Family hardiness acts as a stress resistance resource by buffering the effects of stress and facilitating adaptation at both the individual and family level; thus, congruency between mothers and spouse/partners family hardiness, particularly in families facing chronic illness, helps both mothers and their spouse/partners in living with chronic illness.

In this study, both mothers and their spouse/partners had lower mean family hardiness scores compared to samples from previous studies. Family hardiness consists of three interrelated components: commitment, challenge and control. Commitment implies a sense of meaningfulness of life; control encompasses the belief that one can influence the course of events and challenge reflects the belief that it is normal for life to change and that change brings about stimulation and growth rather than presenting a threat to security. Mothers and spouse/partners with lower mean hardiness scores may tend to feel alienated and powerless in the face of stressors, in this case, chronic illness. Chronic illness, particularly chronic illness that is gradual in onset and episodic in nature, may be associated with lower levels of family hardiness due to the numerous complex stressors mothers and spouse/partners experience over time. In addition, it may become more difficult for mothers and spouse/partners to believe that the challenge of living with chronic illness brings an opportunity for growth and positive change once faced with an episodic chronic illness for which there is no cure.

Hypothesis One: Antecedents of uncertainty (education and severity of illness) will be negatively related to uncertainty for mothers and their spouse/partners.

Studies using the uncertainty scales have examined a number of variables as antecedents of uncertainty. These include severity of illness (measured by Life with Chronic Illness Scale in this study), the erratic nature of symptomatology, the ambiguity of symptoms, cues and information from health care providers, personal beliefs, characteristics and abilities, social support, and demographic variables (age, marital status, socioeconomic status, employment, and education).

Severity of illness predicted higher uncertainty levels in a group of women being treated for gynecological cancer (Mishel, 1988). In a later study, Braden (1990) found that illness severity was again a significant positive predictor of uncertainty in women with rheumatoid arthritis. Reoccurrence of the same condition or frequent repeated hospitalizations (aspects of severity) lead to higher levels of uncertainty (Anderson-Stegesten, 1991; Ronayne, 1989; Van Den Borne, 1987; Webster & Christman, 1988). Several researchers (Christman et al., 1988; Mishel, 1984; and Wineman et al., 1993) found education to be an antecedent of uncertainty (lower levels of education resulted in higher levels of uncertainty).

In this study, severity of illness, as measured by the Life with Chronic Illness Scale, and education, were not negatively related to uncertainty for mothers, however, mother's severity of illness was positively correlated with spouse/partners uncertainty in illness, suggesting that the more severe the mothers illness, the higher the uncertainty for spouse/partners, a concern if mothers are relying on their spouse/partner for emotional support.

In previous studies, frequency of hospitalization was used to measure severity of illness along with a number of other variables including the number of both prescription and over the counter medications. In these studies, more frequent hospitalizations, thus the more severe the illness, the higher the level of uncertainty (Andersson-Stegesten, 1991; Ronayne, 1989; Van Den Borne, 1987; Webster & Christman, 1988). In this study, the number of times mothers were hospitalized for chronic illness in the last 12 months was positively correlated with uncertainty in illness for mothers ($r = .32$, $p < .01$). The four characteristics of uncertainty are ambiguity, vagueness, unpredictability and a lack of information. Mothers experiencing repeat hospitalizations are possibly dealing with one or more of these elements of uncertainty.

Age at diagnosis was positively correlated with uncertainty in illness indicating the older the mother at the time of her diagnosis of chronic illness, the higher the level of uncertainty. A possible explanation could be that since it took a while to get the official diagnosis of chronic illness, uncertainty increased over time with the delay in diagnosis. This contradicts the finding by Brandon that the severity of illness is negatively correlated with uncertainty if reasoning for this is that the more severe the illness, the more advanced the degree of illness, the more knowledge the mother has of her illness, the less uncertainty.

Mothers were asked about the use of complementary therapies to manage their chronic illness. Exercise was listed as a complementary therapy and levels of uncertainty were positively correlated with exercise indicating that mothers may use exercise to manage the uncertainty of chronic illness.

The number of children from prior marriage/relationships was positively correlated to uncertainty in illness, possibly indicating that mothers who have children from prior marriages (n

= 23) are older and thus their chronic illness is more advanced, leading to higher levels of uncertainty. In addition, mothers with children from prior marriages may have more children, thus putting more strain on mothers with chronic illness. These mothers may have less time for learning about their chronic illness as well as less time for managing the illness.

Mothers' severity of illness was positively correlated with spouse/partner's uncertainty, indicating spouse/partners reported higher levels of uncertainty associated with mothers' higher illness severity. A possible explanation for this finding could be that when faced with the chronicity of the illness, families experience more unpredictability and complexity surrounding the illness, which is associated with higher levels of uncertainty for spouse/partners (See Table 11). In addition, as mothers face higher illness severity, spouse/partners experience more uncertainty about the management of family life and care of the children in the family. Qualitative data from this study suggest that spouse/partners face increasing uncertainty associated with mothers' illness severity.

Spouse/partners:

> "It's been a bit difficult to cope since I am a person who likes to be "on the go" quite a bit and with two young children and a mother diagnosed with fibromyalgia, that creates some friction. I think I've been pretty patient with the condition, although I could probably be even more cooperative and understanding."

> "Be patient with each other. Be honest with each other, especially about limitations and expectations. Help educate each other about the illness and also educate children who are old enough to understand- so they aren't "in the dark" on why "mom" is feeling this way. Stay positive and nurturing."

Hypothesis Two: Uncertainty will be a significant negative predictor of psychological wellbeing for mothers and their spouse/partner.

In this study, uncertainty was not a significant negative predictor of psychological wellbeing for mothers or spouse/partners (See Table 12). Therefore, this hypothesis was not supported. These findings were in contrast to what the researcher expected based on previous research in which uncertainty was a negative predictor of psychological wellbeing.

Hawthorne and Hixon (1994), in a sample of 24 adults with chronic heart failure, found uncertainty related to poorer mood disturbances during hospitalization and at 1, 3, & 6 months post discharge from the hospital. This was consistent with Webster and Christman's (1988) findings in 20 adults at 6 – 8 days post discharge following hospitalization due to a myocardial infarction.

In three different studies of adults with multiple sclerosis, uncertainty was associated with more psychological distress. In 118 adults with progressive multiple sclerosis (Wineman, 1990) uncertainty was positively associated with depression. In 1993, Wineman, O'Brien, Nealon, and Kaskel, studied 61 couples in which one spouse had multiple sclerosis and found uncertainty was positively associated with negative mood states for the family member with chronic illness. In a larger study of 433 individuals with multiple sclerosis and 257 individuals with spinal cord injuries, Wineman, Durand, and Steiner (1994), found uncertainty was negatively associated with emotional wellbeing.

A possible explanation for the unexpected finding could be that mothers and spouse/partners experiencing uncertainty have learned to live with chronic uncertainty. Mishel's (1990) later

Uncertainty in Illness framework, based on Chaos Theory, suggests that individuals living with chronic illness learn, over time, to live with chronic uncertainty. Qualitative data from this study suggests mothers and spouse/partners develop strategies to learn to manage their chronic illness such as living one day at a time and making short-term goals and plans. These strategies help families to live a "normal" life and possibly keep uncertainty to a manageable level to the point where uncertainty no longer predicts mothers or spouse/partners psychological wellbeing.

Hypothesis Three: Family hardiness will be a significant positive predictor of psychological wellbeing for mothers and their spouse/partner.

This hypothesis was supported. Family hardiness was a significant positive predictor of psychological wellbeing for both mothers and spouse/partners in this study. These findings provide support that stress resistance resources, such as family hardiness, predict psychological wellbeing in family members experiencing chronic illness. These findings are congruent with the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993; 1996), where it is predicted that resiliency factors such as family hardiness influence the wellbeing of family members.

Hypothesis Four: Family hardiness will function as a moderator between uncertainty and psychological wellbeing for mothers and their spouse/partner.

For mothers, 34.7% of the variance in psychological wellbeing was explained with the demographic variables and family hardiness, which were significant; however, uncertainty and the moderating interaction term were not significant (See Table 14).

For spouse/partners, 35.1% of the variance in psychological wellbeing was explained with the demographic variables and family hardiness, which were significant; however uncertainty and the moderating interaction term were not significant (See Table 15).

This hypothesis was not supported for mothers or spouse/partners. The lack of significant interaction effects was contradictory to the researcher's expectation.

One explanation for the lack of statistically significant interaction effects could be the small sample size of mothers and spouse/partners participating in the study and therefore lack of power to reach the significance level. Moderation required a sufficient sample size in each of four cells: 1). Mothers and spouse/partners who scored high on uncertainty and high on family hardiness; 2). Mothers and spouse/partners who scored high on uncertainty and low on family hardiness; 3). Mothers and spouse/partners who scored low on uncertainty and high on family hardiness; and 4). Mothers and spouse/partners who scored low on uncertainty and low on family hardiness.

In addition, the rule of thumb for regression analyses is one independent variable for 10 subjects; with an N of 30 for spouse/partners and 4 independent variables (significant demographics, uncertainty, family hardiness, uncertainty x family hardiness), the study needed a minimum of forty spouse/partners to reach significance.

A second explanation could be that family hardiness functions as a mediator but not a moderator in the relationship between uncertainty and psychological wellbeing. For hardiness to act as a mediator, the correlation between uncertainty and mothers and spouse/partners psychological wellbeing will have to be significant but needs to become insignificant when family hardiness is added. However, because there is no significant relationship between uncertainty and psychological wellbeing, which is the first criteria for mediation, it is not plausible to have a mediating effect for family hardiness.

Hypothesis Five: Congruency between mothers' and spouse/partners' levels of uncertainty and family hardiness will be a significant positive predictor of psychological wellbeing for mothers and spouse/partners.

In this study, congruency between mothers' and spouse/partners' levels of uncertainty and family hardiness was not a predictor of psychological wellbeing for mothers or spouse/partners (See Table 16). This was contrary to what the researcher expected to find. A possible explanation may be that a mother reporting low levels of uncertainty may help balance a spouse/partner reporting high levels of uncertainty and vice versa. The same could be true for family hardiness; indicating a family member reporting high levels of family hardiness may help balance a family member reporting low levels of family hardiness.

A second explanation for the nonsignificant finding could be the small sample size used to create congruency scores. There were only 30 spouse/partners in this sample; thus, congruency scores could only be calculated for 30 mothers and their spouse/partners.

Research Question One: How have you dealt with the uncertainty of chronic illness?

Education about the illness as a way to deal with the uncertainty of chronic illness was an important strategy for mothers and their spouse/partners. Learning about the illness included learning about the disease itself as well as learning what brings on episodes of chronic illness. This finding is consistent with previous research on uncertainty management. The major method used to manage uncertainty in previous studies was to restructure life to include the unpredictability of symptom onset (Baier, 1995; Becker et al., 1993; Small & Graydon, 1993; Weitz, 1989). This restructuring included learning to live one day at a time, being more cautious, pacing themselves, being more aware of signs of danger, and getting to know the illness better. Qualitative data from this study suggested learning to live one day at a time, pacing themselves (getting rest and trying to prioritize life) and getting to know the illness better were strategies used by mothers and spouse/partners to deal with the uncertainty of chronic illness.

Learning about the illness helped families in maintaining a sense of "normalcy" in their lives, which was important for mothers and their spouse/partner. Learning about the illness included learning about the symptoms as well as ways to manage or control the symptoms of their illness in an effort to live a more "normal" family life. Mothers and spouse/partners also believed it was important to learn about the illness in order to teach their children about the illness, including providing children with additional information as they learned more about the illness.

Mothers and spouse/partners suggested it was important to maintain a positive attitude in dealing with the chronic illness in an effort to make life as "normal" as possible for their families. Robinson's qualitative work (1993) supports this finding, suggesting there is a focus on normalization for families managing chronic conditions. Rehm and Catanzaro (1998) examined family members' perceptions of the effect of chronic illness on parenting. Using a symbolic interactionism framework, Rehm and Catanzaro's findings indicate the goal of family life for these families was to make life as normal as possible. Parents cited a positive attitude and a supportive spouse as contributing to successful parenting and family life. The results of this study point to the importance of normalization for these families.

Creative problem solving was a strategy used by mothers and spouse/partners to help deal with the uncertainty of chronic illness. These strategies included trying to simplify life and not planning too far in the future. This finding was also supported in previous research (Robinson, 1998) where families changed their priorities and tried to simplify their lives in order to manage the unpredictability of chronic illness.

Research Question Two: What advice do you have for other mothers with chronic illness and their spouse/partners?

Education about the illness was again mentioned as being an important aspect of living with chronic illness. Mothers and spouse/partners suggested learning about the chronic illness was helpful in managing their disease as well as educating others about the symptoms of the disease. Individuals who reported they needed information to make the future more predictable viewed lack of information as a source of uncertainty in several studies in different populations (Mason, 1985; Moser, Clements, Brecht, & Weiner, 1993; Nyhlin, 1990; Small & Graydon, 1993; Weems & Patterson, 1989). Learning about the illness helped in maintaining normalcy and a sense of control, which was advice from mothers and their spouse/partners to other families living with mothers with chronic illness. This study supports previous findings on the importance of knowledge about their chronic illness.

Seeking support was identified by mothers and their spouse/partners as being an important aspect of living with chronic illness. Mothers and their spouse/partners suggested families ask for help from others in dealing with chronic illness. This help included help from other family members as well as support groups and others with chronic illness. In Robinson's work (1998), women found themselves "falling down and falling apart" during Stage Two of a four-stage theory of women's evolving relationship with the family member called "chronic illness". During stage two, women experience illness-related losses. Losses include, among others, the loss of the sense of family intactness as well as the loss of family support. Robinson (1998) reported that once these women fell down, there was no one there to pick them up. This lack of support was devastating to these women. Family members stated they knew something was wrong but didn't realize how serious the problem was or that the women needed assistance. This points to the importance of asking for help and support when needed.

Living for today included changing priorities in an effort to live with chronic illness. Mothers reported learning to let go of the little things and choosing priorities differently. This finding fits with previous research by Robinson (1998) in which mothers suggest that in an effort to make life as normal as possible, they make trade offs in their lives i.e. forgoing a perfectly clean house for time spent with children. These findings support previous research on families trying to live a life with chronic illness.

Lastly, spouse/partners shared their experiences in living with a mother with chronic illness. One of the difficulties expressed by spouse/partners in this study was their tendency to forget the chronic illness existed when there was a lack of visible signs of chronic illness in their spouse/partner. Mothers also identified the lack of visible symptoms as being a problem in their family life. Visible signs of illness, although having the potential disadvantage of stigma and shame, do permit others to gauge their interactions in a more objective way than is the case with invisible signs of illness (Rolland, 1994). Invisible signs of illness foster ambiguity in a number of ways. For some family members, it is easier to deny or minimize symptoms that are "out of sight, out of mind" (Rolland, 1994). This becomes more complicated as mothers often conceal or hide symptoms of chronic illness in an effort to make life appear as "normal" as possible (Robinson, 1998). Thus, chronic illness symptoms become difficult to assess and manage for the mother with the chronic illness as well as the spouse/partner if they are trying to make life appear as normal as possible in an effort to manage chronic illness.

Research Question Three: Is there anything else you would like to tell us about living with chronic illness?

Mothers and their spouse/partners again mentioned the importance of learning about the disease process, maintaining control over the chronic illness, and trying to live as "normal" a life as possible. Mothers and their spouse/partners also mentioned the frustrations and anger they felt in living with chronic illness as well as the repeated frustrations regarding the lack of visible symptoms. In addition, both mothers and spouse/partners identified a positive attitude as being an important element in managing life with chronic illness. Rehm & Catanzaro (1998) suggest both parents and children mostly thought of their family as functioning well, despite the many changes brought about by the chronic illness. Parents cited a positive attitude and a supportive spouse as contributing to successful parenting and family life (Rehm & Cantanzaro, 1998).

Linking Study Results to Theoretical Frameworks

Family Systems Theory

Family Systems Theory can be used to understand intrafamily processes such as family functioning, family communication, family conflict, separateness and connectedness among members, cohesion, integration, and adaptation to change (Whitchurch & Constantine, 1993). Family Systems theory also considers subsystems which includes individuals in the family and the various subsystems to which he/she belong, and suprasystems, which include extended family, culture, community, geographic region, and national system. Families faced with a family member living with chronic illness must learn new roles and rules to deal with life with chronic illness. Qualitative data in this study addresses the effects of chronic illness on the mother living with the chronic illness but also the spill over effect of chronic illness on other family members, particularly the spouse/partner. In addition to themes of education, seeking support, creative problem solving, and living for today as efforts to manage or control chronic illness, mothers and their spouse/partners identified difficulties and frustrations they felt living with chronic illness. Families were required to change and reorganize in numerous complex ways in order to adapt to a new level of functioning. Mothers and spouse/partners identified strategies they were using, such as simplifying their lives and changing priorities, in order to make changes and reorganize to adapt to this new level of functioning.

Mothers and spouse/partners responses suggested that the stress they experienced in living with chronic illness affected the entire family system, including children in the family. It is important for health care professionals to remember that these families are experiencing normal developmental stressors in addition to the stress of chronic illness which may make the family even more vulnerable to crisis. Results of this study suggest focusing on interventions to promote family hardiness may help families learning to live with chronic illness.

The Resiliency Model of Family Stress, Adjustment and Adaptation

In the adjustment phase of the model, families are able to make only minor changes in their level of functioning in order to achieve a satisfactory level of adjustment (bonadjustment) (See Figure 1). If these minor changes do not result in a satisfactory level of adjustment, the family experiences a crisis situation, which heralds the onset of the adaptation phase. In illness situations, particularly chronic illness, problems are often numerous and complex, demanding more substantial changes in the family system. Families now require new patterns of functioning in order to restore stability, order and a sense of coherence.

The level of family adaptation is determined by several interacting components (McCubbin & McCubbin, 1993). In this study, uncertainty was considered an element of the pileup (AA) of demands on or in the family system created by the illness. Thus, uncertainty interacts with the family's level of regenerativity or resiliency (R). These components interact with the family's resources (BB); in this case, family hardiness is considered a stress resistance resource for the family. A situational appraisal (CC) is formed from the perceived relationship between the family's resources and the demands of the chronic illness. The family appraisal of the crisis situation (CC) interacts with the family's schema appraisal (CCC). This interaction creates a family meaning that is attached to the illness and the changes it produces. The resource and appraisal components then interact with the family's problem solving and coping repertoire (PSC) to facilitate family adaptation to the chronic illness.

In this study, family hardiness acted as a stress resistance resource for mothers and spouse/partners. Family hardiness scores were lower in these families compared to samples from previous studies. A possible explanation could be that the demands of the chronic illness place a heavy strain on these families; thereby making it difficult to consistently do well in the three characteristics of family hardiness: commitment, challenge, and control. The demands of the chronic illness may, over time, overwhelm the family's resources, including family hardiness. In this study, family hardiness was a consistent predictor of psychological wellbeing, which suggests the importance of family hardiness for families living with chronic illness.

The process of acquiring, allocating, and using resources for meeting the demands of living with chronic illness is a critical aspect of family stress, adjustment, and adaptation (McCubbin, M. A. et al., 1993). The Resiliency Model of Family Stress, Adjustment, and Adaptation characterizes the family system as a resource-exchange network in which problem solving and coping are the actions for this exchange.

Coping, according to the Resiliency Model, is defined as a specific effort (covert or overt) by which an individual family member or the family as a whole attempts to reduce or manage a demand on the family system and bring resources to bear to manage the situation (McCubbin, M. A. et al., 1993). In previous work (McCubbin, M. A. et al., 1993) with families faced with a crisis, four broad headings emerged as characterizing the ways in which coping facilitates adaptation:

(1) Coping may involve reallocating resources to eliminate or reduce the number and intensity of demands created by the illness. In this study, families reported a number of creative problem-solving strategies such as changing priorities, working together as a team, simplifying their lives and trying to live life as normally as possible.

(2) Coping may involve acquiring additional resources not already available to the family. Mothers and spouse/partners reported seeking support, both emotional as well as tangible aid, as strategies employed to manage life with chronic illness. Seeking support included communicating with and asking for help from other family members, friends, church members, and others living with chronic illness.

(3) Coping may involve managing the tension associated with ongoing illness strains. Families reported a number of strategies used to manage the tension associated with living with chronic illness. These strategies included exercising, getting enough rest, taking vitamins, paying attention to nutritional needs, maintaining a sense of humor, taking prescription and over the counter medications, and the use of complementary therapy. Families also mentioned the importance of maintaining normalcy and trying to control the illness rather than letting the illness control you as a way to manage life with chronic illness.

(4) Coping may involve a reappraisal of the situation to make it more manageable and acceptable. This strategy for coping interacts directly with what is labeled as Family Schema appraisal in the Resiliency Model (McCubbin, M. A. et al., 1993). In this study, families identified efforts to reduce role strain by lowering home expectations of the mother with chronic illness. Mothers reported that they were going to control the chronic illness rather than letting it control them. One of the spouse/partners used downward comparison in talking about life with

chronic illness when he stated that there is always someone worse off than you. Both mothers and spouse/partners voiced the importance of maintaining an optimistic outlook and acceptance of the situation. Families stated they were working together as a team to make the most out of a tough situation. These are all examples of coping by reappraising the meaning of living life with a chronic illness.

Coping and problem solving may be directed at the reduction or elimination of stresses, the acquisition of additional resources, the ongoing management of tension, and shaping the appraisal at both the situational and the schema level (McCubbin, M. A. et al, 1993). This research speaks to the ability of families to use these coping strategies to manage life with chronic illness.

Implication for Nursing Research and Practice

In order for researchers and health care professionals to understand the family's life with chronic illness, this study's qualitative and quantitative results indicate it is important to assess the families' levels of uncertainty, family hardiness, and psychological wellbeing. By assessing the role of uncertainty, and family hardiness on families, interventions can be offered that benefit the whole family. Such interventions could not only benefit the mother with chronic illness but other family members as well who are trying to live with a mother with chronic illness.

Nurses working with families of mothers with chronic illness need to be aware of the effects of chronic illness on psychological wellbeing. Discussing with families their concerns related to their illness and providing them with information about their illness, would therefore be of importance for nurses working with families. Families living with chronic uncertainty may have learned to manage their uncertainty through strategies such as living one day at a time and making short-term goals. Health care providers can support these families' efforts to continue to manage their chronic uncertainty.

This study found that family hardiness was an important predictor of psychological wellbeing for mothers and their spouse/partner. Researchers and health care professionals can focus their interventions on promoting family hardiness.

In order to understand the role of resiliency factors in families and how family stress resistance resources function when families are experiencing stress life situations, such as dealing with chronic illness, researchers need to study uncertainty in illness and family hardiness further. In this study, family hardiness was viewed as a stress resistance resource or a resiliency factor.

Based on the findings of the role of the resiliency factor (family hardiness) in families with mothers living with chronic illness, health care professionals may want to focus their interventions on strengthening the control, commitment, and the challenge components of family hardiness. To strengthen the control component of family hardiness, health care professionals can assist families in learning how to monitor and control the symptoms of the chronic illness as well as providing education to families about the disease process itself as well as how to live a life with chronic illness. Such interventions may help families feel they are in better control over their family life, that they are able to manage having a mother with chronic illness, may help families feel more confident in using their resources to meet the families needs, and may increase the mother and spouse/partners general sense of psychological wellbeing.

To strengthen the co-oriented commitment component of family hardiness, health care providers and researchers can encourage families to work together as a team and to help the mother with chronic illness. Qualitative results from this study suggest families deal with chronic illness by helping the ill family member as much as possible and using a "team effort" approach to living with chronic illness.

To strengthen the challenge component of family hardiness, health care providers and researchers can help families view chronic illness as a challenge rather than a burden. In this study, families reported that they were determined to control their illness rather than letting the illness get the better of them. In addition, they addressed strategies used to manage the frustrations and anger they felt at living a life with chronic illness such as living a day at a time and planning for the short term. Qualitative data from this study supports the use of challenge as a component of family hardiness in living with chronic illness.

Strengths and Limitations of the Research

There are several limitations to this study. The first limitation is that families who volunteered to participate in the study are self selected and might not be representative of all families of mothers with chronic illness.

A second limitation was the use of self-report measures (questionnaires) as a method of data collection. Mothers and their spouse/partner may lack objectivity in perceptions (be influenced by other family members or social desirability) when responding to items on the instruments. Families of mothers with chronic illness may also be interested in expressing other concerns than are mentioned in the questionnaires, thus the rationale for the open ended questions asking mothers and their spouse/partner how they deal with the uncertainty of chronic illness, their advice for other families living with a mother with chronic illness and anything else they wanted to share regarding life with chronic illness. There may still be other concerns that might be unique to their family life. Using a mailed survey rather than an in home data collection could also be viewed as a limitation as this limits the families' accessibility to ask the researcher to clarify questions, although the researcher did call families at one week intervals to answer any questions families may have had when completing the questionnaires.

A third limitation of this study was the homogeneity of the sample. The majority of the sample consisted of white, middle class families from the Midwest. Therefore, based on the geography where the data was collected, access to families of different ethnicity and location was limited, which limits the generalizability of the study.

A fourth limitation of this study could be that 50% of the mothers in the study had fibromyalgia. A population of mothers with a more diverse range of chronic illnesses may have made a difference in the results of the study.

The last limitation to this study was the small sample size for both mothers and their spouse/partners, but especially for spouse/partners. Although 71% of the mothers' total number (N = 60) of spouse/partners responded, there were only a total of 30 spouse/partners from which to analyze data. A larger sample of spouse/partners may have resulted in additional statistically significant results.

There are several strengths to this study. The first strength is that although there was a small total sample size, the response rate for mothers was 52%; of those mothers having a spouse/partner, 71% (n = 30) of those spouse/partners participated in the study. In addition, there was very little missing data in the study. One mother did not complete the Life with Chronic Illness questionnaire and one spouse/partner did not complete the Psychological Wellbeing Scale. Mean substitution scores were used for missing data.

A third strength to this study is that the study included obtaining both qualitative and quantitative data in an effort to obtain a better understanding of life with chronic illness. In this study, the qualitative data supported the quantitative data regarding the importance of family hardiness in predicting psychological wellbeing for mothers and their spouse/partners. In addition, the qualitative data was rich in description of how mothers and their spouse/partners were dealing with living with chronic illness, including managing the uncertainty of chronic illness. Qualitative data supported previous research, which suggested that living with the uncertainty of chronic illness was negatively associated with psychological wellbeing; however, the quantitative data did not reflect this finding.

A fourth strength is that the study supports the theoretical frameworks chosen as the foundation of the study. Family hardiness was a significant predictor of psychological wellbeing for mothers and spouse/partners, indicating family hardiness did act as a stress resistance resource for both mothers and spouse/partners. Qualitative and quantitative data suggest the significance of the impact of chronic illness, including the importance of uncertainty and family hardiness, on all family members, not only the mother living with chronic illness, which supports the Family Systems framework.

Recommendations for Future Research

This study did not find any moderating effects of family hardiness on uncertainty and psychological wellbeing. Replicating this study with a larger sample size would be important. Future research should be conducted to see if the relationship between uncertainty and psychological wellbeing for mothers and their spouse/partner is significant.

Studying uncertainty, family hardiness and psychological wellbeing in families in which the mother has chronic illness would be important in other cultures, since the majority of the families in this study were Euro-American.

It would be important to conduct comparison studies on mothers with other types of chronic illness, possibly illnesses which are sudden in onset and progressive in nature, to examine the effect of the psychosocial type of the chronic illness on uncertainty, family hardiness and psychological wellbeing.

Future research on families of mothers with chronic illness and their spouse/partner should also focus on nursing interventions. Interventions focusing on strengthening family hardiness would be important for families living with chronic illness.

Conclusion

Mothers with chronic illness and their spouse/partner face many challenges in living with chronic illness. It is important for families living with chronic illness to learn to manage their chronic illness in order to live as "normal" a family life as possible. Health care services are shrinking and families are given more responsibility to care for family members living with chronic illness. Nurses need to empower families, focusing on family strengths and resiliency factors such as family hardiness in an effort to promote the psychological wellbeing of all the family members.

Armstead, L., Kleink K. and Forehand, R. (1995). Parental physical illness and child functioning. *Clinical Psychology Review, 15,* 409-422.

Bailey, J. M., & Nielsen, B. I. (1993). Uncertainty and appraisal of uncertainty in women with rheumatoid arthritis. *Orthopaedic Nursing, 12* (2), 63-67.

Barnett, R.C. (1994). Home-to-work spillover revisited: A study of full-time employed women in dual-earner couples. *Journal of Marriage and the Family, 56,* 647-656.

Baier, M. (1995). Uncertainty of illness for persons with schizophrenia. *Issues in Mental Health Nursing, 16,* 201-212.

Becker, G., Janson-Bjerklie, S., Benner, P., Slobin, K., & Ferketich, S. (1993). The dilemma of seeking urgent care: Asthma episodes and emergency service use. *Social Science and Medicine, 37,* 305-313.

Bennet, S. J. (1993). Relationships among selected antecedent variables and coping effectiveness in post myocardial infarction patients. *Research in Nursing and Health, 16,* 131-139.

Braden, C. J. (1992). Description of learned response to chronic illness: Depressed versus

Christman, N. J., McConnell, E. A., Pfeiffer, C., Webster, K. K., Schmitt, M., & Ries, J. (1988). Uncertainty, coping, and distress following myocardial infarction: Transition from hospital to home. *Research in Nursing and Health, 11,* 71-82.

Crigger, N.J. (1996). Testing an uncertainty model for women with multiple sclerosis. *Advances in Nursing Science, 18,* 37-47.

Dimond, M. (1984). Identifying the needs of the chronically ill. In S.E.Milligan (Ed.), *Community health care for chronic physical illness: Issues and models.* (pp. 1-14). Cleveland: Case Western Reserve University.

Donnelly, E. (1994). Parents of children with asthma: An examination of family hardiness, family stressors, and family functioning. *Journal of Pediatric Nursing, 9,* 398-408.

Dressel, P.L., & Clark, A. (1990). A critical look at family care. *Journal of Marriage and the Family, 52,* 769-782.

Failla, S., & Jones, L.C. (1991). Families of children with developmental disabilities: An examination of family hardiness. *Research in Nursing and Health, 14,* 41-50.

Ferran, C., & Powers, M. (1993). Quality of life of hemodialysis patients. *Association Of Nephrology Nursing Journal, 18,* 173-181.

Fink, S. (1995). The influence of family resources and family demands on the strains and well being of caregiving families. *Nursing Research, 44,* 139-146.

Fleury, J., Kimbrell, L.C., & Kruszewski, M.A. (1995). Life after a cardiac event: Women's experience in healing. *Heart and Lung, 24,* 474-482.

Friedman, Marilyn M. (1998). *Family Nursing: Research, Theory, and Practice.* (4th edition). Stamford Connecticut: Appleton and Lange.

Hahn, M.E. (1966). *California Life Goals Evaluation Schedule.* Palo Alto: Western Psychological Services.

Hawkins, A., Marshall, C. & Meiners, K. (1995). Exploring wives' sense of fairness about family work. *Journal of Family Issues, 16* (6), 693-721.

Hawthorne, M.H., & Hixon, M.E. (1994). Functional status, mood disturbance and quality of life in patients with heart failure. *Progress in Cardiovascular Nursing, 9* (1), 22-32.

Hilton, B. A. (1989). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. *Journal of Behavioral Medicine, 12,* 39-54.

Hilton, B.A. (1988). The phenomenon of uncertainty in women with breast cancer. *Issues in Mental Health Nursing, 9,* 217-238.

Hochschild, A. and Machung, A. (1989). *The second shift.* New York: Avon Books.

Hull, J., Van Treuren, R. & Virnelli, S. (1987). Hardiness and health: A critique and alternate approach. *Journal of Personality and Social Psychology, 53,* 518-530.

Hymovich, D.P., & Hagopian, G.A. (1992). *Chronic illness in children and adults: A psychosocial approach.* Philadelphia: W.B. Saunders.

Jackson, D. N. (1974). *Personality research form manual.* Goshen, New York: Research Psychologists Press.

Janson-Bjerklie, S., Ferketich, S., & Benner, P. (1993). Predicting the outcomes of living with asthma. *Research in Nursing and Health, 16,* 241-250.

Jarret, Robin L. (1996). Welfare stigma among low-income African-American single mothers. *Family Relations, 1,* 368-374.

Johnson, J.L., & Morse, J.M. (1990). Regaining control: The process of adjustment after myocardial infarction. *Heart and Lung, 19,* 126-135.

Kahn, R.L. (1991). Forms of women's work. In M. Frankenhaeuser, U. Lundberg, & M. Chesney (Eds.), *Women, work and health: Stress and opportunities* (pp. 65-83). New York : Plenum.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health, 9,* 215-222.

Kobasa, S.C. (1979a). Personality and resistance to illness. *American Journal of Community Psychology, 7,* 413-423.

Kobasa, S.C. (1979b). Stressful life events, personality, and health: An inquiry into hardiness. *Journal of Personality and Social Psychology, 37,* 1-11.

Kobasa, S.C. (1982a). Commitment and coping in stress resistance among lawyers. *Journal of Personality and Social Psychology, 42,* 707-717.

Kobasa, S.C. (1982b). The hardy personality: Toward a social psychology of stress and health.

In G.S. Sanders & J. Sals (Eds.), *Social psychology of health and illness*, Hillsdale, NJ: Erlbaum.

Kobasa, S.C., Maddi, S.R., & Courington, S. (1981). Personality and constitution as mediators in the stress-illness relationship. *Journal of Health and Social Behavior, 22,* 368-378.

Kobasa, S.C., Maddi, S.R., & Kahn, (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology, 42,* 168-177.

Kobasa, S.C., Maddi, S.R., Puccetti, M.C., & Zola, M.A. (1985). Effectiveness of hardiness, exercise, and social support as resources against illness. *Journal of Psychosomatic Research, 29,* 525-533.

Kobasa, S.C., & Puccetti, M.C. (1993). Personality and social resources in stress resistance. *Journal of Personality and Social Psychology, 45,* 839-850.

Lambert, V., Lambert, C., Klipple, G., & Mewshaw, E. (1990). A study of the relationships among hardiness, social support, severity of illness and psychological well-being in women with rheumatoid arthritis. *Health Care for Women International, 11,* 159-173.

Lambert, V., Lambert, C., Klipple, G. & Mewshaw, E. (1985). The relationship between social support and psychological well-being in rheumatoid arthritic women from two ethnic groups. *Health Care for Women International, 6* (1/2), 405-414.

Landis, B.J. (1996). Uncertainty, spirituality, well-being, and psychosocial adjustment in chronic illness. *Issues in Mental Health Nursing, 17,* 217-231.

Lavee, Y., McCubbin, H. I., & Olson, D. H. (1987). The effect of stressful life events and transitions on family functioning and well-being. *Journal of Marriage and Family, 49* (4), 857-873.

Lazarus, R.S., & Folkman, S. (1984). Stress, appraisal, and coping. *(*pp. 117-140*)*. New York: Springer Publishing Co.

Lewis, F. M. (1986). The impact of cancer on the family: A critical analysis of the research literature. *Patient Education and Counseling, 8,* 269-289.

Lewis, F. M., Hammond, M.A., & Woods, N.F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: An explanatory model. *Journal of Behavioral Medicine, 16,* 351-370.

Lewis, F. M., Woods, N. F., Hough, E. S., & Bensley, L.S. (1989). The family's functioning

Mast, M.E. (1995). Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice: An International Journal, 9*, 3-29.

McHenry, J., Allen, C., Mishel, M.H., & Braden, C.J. (1993). Uncertainty management for women receiving treatment for breast cancer. In S. G. Funk, E. M. Tromquist, M. T.C. Champagne, & R. A. Wiese (Eds.), *Key aspects of caring for the chronically ill: Hospital and home* (pp. 170-177). New York: Springer Publishing Co.

McIntosh, J. (1976). Processes of communication, information, seeking and control associated with cancer: A selective review of the literature. *Social Science and Medicine, 8,* 167-187.

McCubbin, H.I., McCubbin, M.A., Thompson, A.I., Han,S., & Allen, C. (1997). Families under stress: What makes them resilient. *Journal of Family and Consumer Science, Fall,* 2-11.

McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family Assessment: Resiliency, Coping and Adaptation-Inventories for Research and Practice.* Madison, Wisconsin: University of Wisconsin Publishers.

McCubbin, H. I. & Thompson, A. I., Thompson, E. A., Elver, K., & McCubbin, M. A. (1994).

Ethnicity, schema, and coherence: Appraisal processes for families in crisis. In H. I. McCubbin, Thompson, A. I., Thompson, E. A., & J. Fromer (Eds.), *Sense of coherence and resiliency: Stress, coping and health.* (pp. 41-67). Madison: University of Wisconsin System.

McCubbin, H. I. & Thompson, A. I. (1992). Resiliency in families: An east-west perspective. In J. Fischer (Ed.), *East-West directions: Social work practice, tradition and change.* (pp. 103-130). Honolulu, HI: School of Social Work, University of Hawaii.

McCubbin, H. I., Thompson, A. I., Pirner, P., & McCubbin, M. A. (1988). *Family types and strengths: A life cycle and ecological perspective.* Edina, MN: Burgess International.

McCubbin, H.I. & Thompson, A.I. (1987). Family typologies and family assessment. In H.I. McCubbin & A.I. Thompson (Eds.), *Family assessment for research and practice.* (pp. 33-50). Madison, WI: University of Wisconsin.

McCubbin, H. I. & Patterson, J. (1983a). The family stress process: The Double ABCX Model of adjustment and adaptation. *Marriage and Family Review, 6* (1/2).

McCubbin, H. I. & Patterson, J.(1983b). The family stress process: The Double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. Sussman, & J. Patterson (Eds.), *Social stress and the family: Advances and developments in family stress theory and Research.* New York: Haworth.

McCubbin, H.I., Patterson, J., & Wilson, L. (1983). Family Inventory of Life Events and Changes (FILE). In H.I. McCubbin, A.I. Thompson, & M.A. McCubbin (1996). *Family Assessment: Resiliency, coping and adaptation-Inventories for research and practice.* (pp. 103-178). Madison: University of Wisconsin System.

McCubbin, H. I. & Patterson, J. (1981). Family Stressors. In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (1996). *Family assessment: Resiliency, coping and adaptation-Inventories for research and practice.* (p. 833). Madison: University of Wisconsin Publishers.

McCubbin, M.A. (1989). Family hardiness and mastery of complex home care regimen. In L.G. Krentz (Ed.), *National Conference on Family Nursing Proceedings.* Portland Oregon: Oregon Health Sciences University, Department of Family Nursing.

McCubbin, M.A. (1988). Family stress, resources, and family types: Chronic illness in children. *Family Relations, 37,* 203-210.

McCubbin, M. A., & McCubbin, H. I. (1993). Families coping with illness: The Resiliency

Model of Family Stress, Adjustment and Adaptation. In C. Danielson, B. Hamel-Bissel, & P.I. Winstead-Fry (Eds.), *Families, health, and illness: Perspectives on coping and intervention.* New York, NY: Mosby.

McCubbin, M. A. & McCubbin, H. I. (1989) Theoretical orientations to family stress and coping. In C. R. Figley (Ed.), *Treating stress in families.* New York: Brunner/Mazel.

McCubbin, M. A. & McCubbin, H. I. (1987) Family stress theory and assessment: The T-Double ABCX Model of Family Adjustment and Adaptation. In H.I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories for research and practice.* Madison: University of Wisconsin Publishers.

McCubbin, M.A., McCubbin, H.I., & Thompson, A.I. (1986). Family Hardiness Index (FHI). In H.I. McCubbin, A.I. Thompson, and M.A. McCubbin (1996). *Family assessment: Resiliency, coping and adaptation- Inventories for research and Practice.* (pp. 239-305) Madison: University of Wisconsin System.

McGoldrick, M. (1989). Women and the family life cycle. In B. Carter & M. McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (pp. 29-68). Boston: Allyn & Bacon.

Mishel, M.H. (1999). Uncertainty in chronic illness. *Annual review of nursing research, 17,* 269-299.

Mishel, M.H. (1997). *Uncertainty in Illness Scales Manual.* M.H. Mishel, University of North Carolina at Chapel Hill, School of Nursing, CB #7140 Carrington Hall, Chapel Hill, NC 7599-7140.

Mishel, M.H. (1997). Uncertainty in acute illness. *Annual review of nursing research, 16,* J. J. Fitzpatrick & J.S. Stevenson (Eds.). New York: Springer.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship, 22,* 256-262.

Mishel, M.H. (1988a). Uncertainty in illness. *Image: Journal of Nursing Scholarship, 20,* 225-232.

Mishel, M.H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health, 7,* 163-171.

Mishel, M.H. (1983). Adjusting the fit: Development of uncertainty scales for specific populations. *Western Journal of Nursing Research, 5,* 355-370.

effects of physical disability on parenting. Unpublished doctoral dissertation, University of San Francisco.

Moser, D.K., Clements, P.J., Brecht, M.L., & Weiner, S.R. (1993). Predictors of psychosocial adjustment in systemic sclerosis: The influence of formal education level, functional ability, hardiness, uncertainty, and social support. *Arthritis and Rheumatism, 36,* 1398-1405.

Mukherjee, S., Sloper, P., & Turnbull, A. (2002). Insight into the experiences of parents with inflammatory bowel disease. *Journal of Advanced Nursing, 37* (4), 355-363.

Nelson, J.P. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science, 18,* 59-76.

Nyhlin, K.T. (1990). Diabetic patients facing long-term complications: Coping with uncertainty. *Journal of Advanced Nursing, 15,* 1021-1029.

O'Brien, R.A., Wineman, N.M., & Nealon, N.R. (1995). Correlates of the caregiving process in multiple sclerosis. *Scholarly Inquiry for Nursing Practice, 9,* 323-342.

O'Neil, R., & Greenberger, E. (1994). Patterns of commitment to work and parenting: Implications for role strain. *Journal of Marriage and the Family, 56,* 101-118.

Osmond, M. & Thorne, B. (1993). Feminist Theories: The social construction of gender in families and society. Chapter 23 in Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W., and Steinmetz, S. (Eds.). 1993. *Sourcebook of Family Theories and Methods: A Contextual Approach.* New York: Plenum.

Parcel, Toby L., & Menaghan, Elizabeth G. (1994). Early parental work, family social capital, and early childhood outcomes. *American Journal of Sociology, 99,* 972-1009.

Pelletier-Hibbert, M. & Sohi, P. (2001). Sources of uncertainty and coping strategies used by family members of individuals living with end-stage renal disease. *Nephrology Nursing Journal, 28,* 411-419.

Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum, 24,* 1343-1353.

Peters, L.C., & Esses, L.M. (1985). Family environment as perceived by children of chronically ill parent. *Journal of Chronic Disease, 38,* 301-308.

Pool, R. (1989). Chaos theory: How big an advance? *Science, 245,* 26-28.

Pollin, I. (1994). *Taking charge: Overcoming the challenge of long-term illness.* New York: Random House.

Pollock, S.E. (1989). Adaptive responses to diabetes mellitus. *Western Journal of Nursing Research, 11,* 265-280.

Pollock, S.E. (1986). Human responses to chronic illness: Physiologic and psychological adaptation. *Nursing Research, 35,* 90-95.

Pollock, S.E., Christian, B.J., & Sands, D. (1990). Responses to chronic illness: Analysis of psychological and physiological adaptation. *Nursing Research, 39,* 300-304.

Redeker, N.S. (1992). The relationship between uncertainty and coping after coronary bypass surgery. *Western Journal of Nursing Research, 14,* 48-64.

Regan-Kubinski, M.J., & Sharts-Hopko, N. (1995). Illness cognition of HIV-infected mothers. *Issues in Mental Health Nursing, 16,* 327-344.

Rehm, R.S., & Catanzaro, M.L. (1998). "It's just a fact of life": Family member's perceptions of parental chronic illness. *Journal of Family Nursing, 4* (1), 21-40.

Rich, V.L., & Rich, A.R. (1987). Personality hardiness and burnout in female staff nurses. *Image: Journal of Nursing Scholarship, 19,* 63-66.

Robinson, C.A. (1998). Women, families, chronic illness, and nursing interventions: from burden to balance. *Journal of Family Nursing,* 4 (1), 271-290.

Robinson, C.A. (1993). Managing a life with a chronic condition: The story of normalization. *Qualititative Health Research, 3* (1), 6-28.

Rolland, J. (1994). The psychosocial typology of illness. *Families, illness, and disability.* (pp.19-42). New York: Basic Books.

Ronayne, R. (1989). Uncertainty in peripheral vascular disease. *Canadian Journal of Cardiovascular Nursing 1* (2), 26-30.

Rotter, J.B., Seeman, M., & Liverant, S. (1962). Internal vs. external locus of control of reinforcement: a major variable in behavior theory. In N. F. Washburne (Ed.), *Decisions, values, and groups.* New York: Pergamon Press.

Rowat, K. M., & Knafl, K. A. (1985). Living with chronic pain: The spouse's perspective. *Pain, 23,* 259-271.

Ryff, C. (1995). Psychological well-being in adult life. *Current Directions in Psychological Science, 4,* 99-104.

Ryff, C. (1989). Happiness is everything, or is it? Explorations of the meaning of psychological well-being. *Journal of Personality and Social Psychology, 57,* 1069-1081.

Ryff, C. & Singer, B. (1996). Psychological well-being: Meaning, Measurement, and Implications for psychotherapy research. *Psychotherapy and Psychosomatics, 65,* 14-23.

Small, S.P., & Graydon, J.E. (1993). Perceived uncertainty, physical symptoms, and negative mood in hospitalized patients with chronic obstructive pulmonary disease. *Heart and Lung, 21,* 568-574.

Smeltzer, S.C. (1994). The concerns of pregnant women with multiple sclerosis. *Qualitative Health Research, 4,* 497-501.

Sormanti, M. & Kayser, K. (2000). Partner support and changes in relationships during life-threatening illness: Women's perspectives. *Journal of Psychosocial Oncology, 18* (3), 45-66.

Spitze, G. (1988). Women's employment and family relations: A review. *Journal of Marriage* *and the Family, 50* (3), 595-618.

Stetz, K., Lewis, F.M., & Houck, G.M. (1994). Family goals as indicants of adaptation during chronic illness. *Journal of Public Health Nursing, 11,* 385-391.

Stryker, Sheldon & Statham, Anne. (1985). Symbolic interaction and role theory. *The Handbook of Social Psychology, 1,* 311-378.

SPSS, Inc. (1993). *SPSS base system syntax reference guide.* Old Tappans, N. J.: Prentice-Hall Publishers.

Svavarsdottir, E.K., McCubbin, M.A., & Kane, J.H. (2000). Well-Being of parents of young children with asthma. *Research in Nursing and Health, 23,* 346-358.

Thorne, S.E. (1990). Mothers with chronic illness: A predicament of social construction. *Health Care for Women International, 11,* 209-221.

Van Den Borne, H.W., Pruyn, J.F.A., & Van Den Heuvel, W.J.A. (1987). Effects of contacts between cancer patients on their psychosocial problems. *Patient Education and Counseling, 9,* 33-51.

Volicer, B.J., Eisenberg, M.A., & Burns, M.W. (1977). Medical-surgical differences in hospital stress factors. *Journal of Human Stress, 3,* 3-13.

Von Bertalanffy, L. W. (1968). *General Systems Theory: Foundations, Development, and Applications.* New York, NY: George Braziller.

Walker, A. J. (1990). Gender and families. In National Council on Family Relations. *2001: Preparing families for the future.* (pp, 16-17). Minneapolis, MN: National Council on Family Relations.

Walker, L. O. & Avant, K. C. (1989). *Strategies for theory construction in nursing.* Norwalk, Connecticut: Appleton-Century-Crofts.

Warrington, K., & Gottlieb, L. (1987). Uncertainty and anxiety of hysterectomy patients during hospitalization. *Nursing Papers Perspective in Nursing, 19,* 59-73.

Webster, D.C., & Brennan, T. (1995). Use and effectiveness of psychological self-care strategies for interstitial cystitis. *Health Care for Women International, 16,* 463-475.

Webster, K. K. & Christman, N. J. (1988). Perceived uncertainty and coping post myocardial infarction. *Western Journal of Nursing Research, 10,* 396-398.

Weems, J., & Patterson, E.T. (1989). Coping with uncertainty and ambivalence while awaiting a cadaveric renal transplant. *Anna Journal, 16,* 27-31.

Weitz, R. (1989). Uncertainty and the lives of persons with autoimmune deficiency syndrome. *Journal of Health and Social Behavior, 30,* 270-281.

Whitchurch, G.G. & Constantine, L. (1993). Systems Theory. In Boss, P.G., Doherty, W.J., LaRosa, R., Schumm, W.R., & Steinmetz, S.K. *Sourcebook of Family Theories and Methods: A Contextual Approach.* New York: Plenum Press.

Wineman, N.M. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research, 39,* 294-299.

Wineman, N. M., Schwetz, K. M., Goodkin, D. E., & Rudick, R. A. (1996). Relationships among illness uncertainty, stress, coping, and emotional well-being at entry into a clinical drug trial. *Applied Nursing Research, 9,* 53-60.

Wineman, N. M., Durand, E. J., & Steiner, R. P. (1994). A comparative analysis of coping behaviors in persons with multiple sclerosis or a spinal cord injury. *Research in Nursing and Health, 17,* 185-194.

Wineman, N.M., O'Brien, R.A., Nealon, N.R., & Kaskel, B. (1993). Congruence in uncertainty between individuals with multiple sclerosis and their spouses. *Journal of Neuroscience Nursing, 25,* 356-361.

Woods, N.F., & Lewis, F.M. (1995). Women with chronic illness: Their views of their families' adaptation. *Health Care for Women International, 16,* 136-148.

Wong, C., & Bramwell, L. (1992). Uncertainty and anxiety after mastectomy for breast cancer. *Issues in Mental Health Nursing, 15,* 363-371.

Wright, L.M., & Leahey, M. (2000). *Nurses and Families Guide to Family Assessment and Intervention.* (3rd edition). Philadelphia: F.A. Davis.

Appendix A

Family Demographic Information

FAMILY BACKGROUND INFORMATION

A. PERSONAL CHARACTERISTICS

1. Sex: male _____
female _____

2. Your age: _______
(write in number)

3. Years of Education: _______
(write in number)

4. Which of the following have you completed: (check *all* that apply to you)

High School Diploma ______ GED ______ Intermediate Certificate/Diploma/ Associate Degree _______

Bachelors Degree ______ Masters Degree ______ Doctorate Degree ______

5. Your Occupation: ____
(write in)

6. Your Employment Status: (check one) Not employed ______ Part-time ______ Full-time _______
Full-time and second job _______

7. Your Spouse/Partner's Occupation: ____
(write in)

8. Your Spouse/Partner's Employment Status: (check one) Not employed ______ Part-time ______
Full-time ______ Full-time and second job _______

9. Your Race: (check one) Asian ______ African American ______ Caucasian ______
American Indian ______ Latino ______ Other _______________ (write in)

B. FAMILY CHARACTERISTICS

10. Present Status: Single ______ Married ______ Separated ______ Divorced ______

Divorced & Remarried ______ Widowed ______ Widowed & Remarried ______

Cohabiting (same or opposite sex) ______

11. Length of Present Marriage/Relationship: _______
(write in years)

Appendix B

Mother's Illness Information

5. **In the last year, how many times have you visited your health care provider due to symptoms (flare-ups) of your chronic illness?**

Number of visits for symptoms of your illness in the last 12 months: __________

6. **In the last year, how many times have you been hospitalized?**

Number of times hospitalized for chronic illness in the last 12 months: ________

Number of times hospitalized for other reasons in the last 12 months: ________

7. **How many different types of medication are you taking for your chronic illness?**

Number of types of medications prescribed by your health care provider: _________

Number of over-the-counter medications: ______________
(eg Tylenol, Antacids, Aspirin, etc.):

8. **Are you using any of the following complementary therapies to manage your chronic illness?**

__________Vitamins/Nutritional therapy

__________ Herbal therapy

__________ Mind/body work (eg relaxation, guided imagery, meditation)

__________ Accupuncture

__________ Accupressure

__________ **Massage**

__________ **Aromatherapy**

__________ **Chiropractics**

__________ **Exercise (eg T'ai Chi, walking)**

__________**Spiritual Care**

__________**Other** **Please list:** ____________________

____

____

____

Appendix C

Life with Chronic Illness

Life with Chronic Illness

The degree to which chronic illness interferes with life often depends on the severity of the illness. Please circle one of the four choices to indicate, at this time, which areas of your life are:

- **Better**
- **No change—going well**
- **No change—not going well**
- **Worse**

My level of energy	Better	No change-- Going well	No change-- Not going well	Worse	
Able to manage own care (feeding, bathing)	Better	No change-- Going well	No change-- Not going well	Worse	
Able to fulfill work responsibilities	Better	No change-- Going well	No change-- Not going well	Worse	N/A
Relationship with spouse or partner	Better	No change-- Going well	No change-- Not going well	Worse	
Relationship with child/ children	Better	No change-- Going well	No change-- Not going well	Worse	
Quality time with relatives	Better	No change-- Going well	No change-- Not going well	Worse	

Quality time with friends	Better	No change-- Going well	No change-- Not going well	Worse
Able to maintain family routines & schedules (eg taking child/children to activities)	Better	No change-- Going well	No change-- Not going well	Worse
Ability to get tasks and chores done at home	Better	No change-- Going well	No change-- Not going well	Worse
Managing my own routines & schedules (eg going to activities)	Better	No change-- Going well	No change-- Not going well	Worse
Managing care of child/ children (eg bathing, feeding)	Better	No change-- Going well	No change-- Not going well	Worse

Appendix D

Uncertainty in Illness Scale

MISHEL UNCERTAINTY IN ILLNESS SCALE-COMMUNITY FORM (MUIS-C) Mother's Form

INSTRUCTIONS:

Please read each statement. Take your time and think about what each statement says. Then circle the answer that most closely measures how you are feeling TODAY. If you agree with a statement, then you would circle either "Strongly Agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then circle "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with me.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

2. I have a lot of questions without answers.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

3. I am unsure if my illness is getting better or worse.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

4. It is unclear how bad my pain is.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

5. The explanations they give about my condition seem hazy to me.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

6. The purpose of each treatment is clear to me.

Strongly Agree	**Agree**	**Undecided**	**Disagree**	**Strongly Disagree**

7. My symptoms continue to change unpredictably.

Strongly Agree Agree Undecided Disagree Strongly Disagree

8. I understand everything explained to me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

9. The doctors say things to me that could have many meanings.

Strongly Agree Agree Undecided Disagree Strongly Disagree

10. My treatment is too complex to figure out.

Strongly Agree Agree Undecided Disagree Strongly Disagree

11. It is difficult to know if the treatments or medications I am getting are helping.

Strongly Agree Agree Undecided Disagree Strongly Disagree

12. Because of the unpredictability of my illness, I cannot plan for the future.

Strongly Agree Agree Undecided Disagree Strongly Disagree

13. The course of my illness keeps changing. I have good and bad days.

Strongly Agree Agree Undecided Disagree Strongly Disagree

14. I have been given many differing opinions about what is wrong with me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

15. It is not clear what is going to happen to me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

16. The results of my tests are inconsistent.

Strongly Agree Agree Undecided Disagree Strongly Disagree

17. The effectiveness of the treatment is undetermined.

Strongly Agree Agree Undecided Disagree Strongly Disagree

18. Because of the treatment, what I can do and cannot do keeps changing.

Strongly Agree Agree Undecided Disagree Strongly Disagree

19. I'm certain they will not find anything else wrong with me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

20. The treatment I am receiving has a known probability of success.

Strongly Agree Agree Undecided Disagree Strongly Disagree

21. They have not given me a specific diagnosis.

Strongly Agree Agree Undecided Disagree Strongly Disagree

22. The seriousness of my illness has been determined.

Strongly Agree Agree Undecided Disagree Strongly Disagree

23. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree Agree Undecided Disagree Strongly Disagree

MISHEL UNCERTAINTY IN ILLNESS SCALE-COMMUNITY FORM (MUIS-C) Spouse/Partner Form

INSTRUCTIONS:

Please read each statement. Take your time and think about what each statement says. Then circle the answer that most closely measures how you are feeling TODAY. If you agree with a statement, then you would circle either "Strongly Agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then circle "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my spouse/partner.

Strongly Agree Agree Undecided Disagree Strongly Disagree

2. I have a lot of questions without answers.

Strongly Agree Agree Undecided Disagree Strongly Disagree

3. I am unsure if my spouse/partner's illness is getting better or worse.

Strongly Agree Agree Undecided Disagree Strongly Disagree

4. It is unclear how bad my spouse/partner's pain is.

Strongly Agree Agree Undecided Disagree Strongly Disagree

5. The explanations they give about my spouse/partner's condition seem hazy to me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

6. The purpose of each treatment is clear to me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

7. My spouse/partner's symptoms continue to change unpredictably.

Strongly Agree Agree Undecided Disagree Strongly Disagree

8. I understand everything explained to me.

Strongly Agree Agree Undecided Disagree Strongly Disagree

9. The doctors say things to me that could have many meanings.

Strongly Agree Agree Undecided Disagree Strongly Disagree

10. My spouse/partner's treatment is too complex to figure out.

Strongly Agree Agree Undecided Disagree Strongly Disagree

11. It is difficult to know if the treatments or medications my spouse/partner are getting are helpful.

Strongly Agree Agree Undecided Disagree Strongly Disagree

12. Because of the unpredictability of my spouse/partner's illness, I cannot plan for the future.

Strongly Agree Agree Undecided Disagree Strongly Disagree

13. The course of my spouse/partner's illness keeps changing. He/she has good and bad days.

Strongly Agree Agree Undecided Disagree Strongly Disagree

14. I have been given many differing opinions about what is wrong with my spouse/partner.

Strongly Agree Agree Undecided Disagree Strongly Disagree

15. It is not clear what is going to happen to my spouse/partner.

Strongly Agree Agree Undecided Disagree Strongly Disagree

16. The results of my spouse/partner's tests are inconsistent.

Strongly Agree Agree Undecided Disagree Strongly Disagree

17. The effectiveness of the treatment is undetermined.

Strongly Agree Agree Undecided Disagree Strongly Disagree

18. Because of the treatment, what my spouse/partner can do and cannot do keeps changing.

Strongly Agree Agree Undecided Disagree Strongly Disagree

19. I'm certain they will not find anything else wrong with my spouse/partner.

Strongly Agree Agree Undecided Disagree Strongly Disagree

20. The treatment my spouse/partner is receiving has a known probability of success.

Strongly Agree Agree Undecided Disagree Strongly Disagree

21. They have not given my spouse/partner a specific diagnosis.

Strongly Agree Agree Undecided Disagree Strongly Disagree

22. The seriousness of my spouse/partner's illness has been determined.

Strongly Agree Agree Undecided Disagree Strongly Disagree

23. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree Agree Undecided Disagree Strongly Disagree

Appendix E

Family Hardiness Index

Appendix F

Psychological Wellbeing Scale

Well-being Scale (Ryff, 1989)

1. **Instructions:** I would like to begin the questionnaire with some general questions about your values and attitudes. Please read each sentence carefully and circle the number that best describes you.

1	2	3	4	5	6
Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree

a. My decisions are not usually influenced by what everyone else is doing.	1	2	3	4	5	6
b. I am good at juggling my time so that I can fit everything in that needs to get done.	1	2	3	4	5	6
c. I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
d. I don't have many people who want to listen when I need to talk.	1	2	3	4	5	6
e. I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
f. I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
g. I have confidence in my opinions even if they are contrary to the general consensus.	1	2	3	4	5	6
h. I tend to worry about what other people think of me.	1	2	3	4	5	6
i. I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
j. I have the sense that I have developed a lot as a person over time.	1	2	3	4	5	6
k. I enjoy personal and mutual conversations with family members and friends.	1	2	3	4	5	6
l. My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6
m. In general, I feel confident and positive about myself.	1	2	3	4	5	6
n. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6

1	2	3	4	5	6
Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree

o. I often change my mind about decisions if my friends or family disagree.	1	2	3	4	5	6
p. I do not fit very well with the people and community around me.	1	2	3	4	5	6
q. When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
r. I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
s. I am an active person in carrying out the plans I set for myself.	1	2	3	4	5	6
t. When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6
u. I think it is important to have new experiences that challenge how I think about myself and the world.	1	2	3	4	5	6
v. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1	2	3	4	5	6
w. I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6
x. I don't want to try new ways of doing things-my life is fine the way it is.	1	2	3	4	5	6
y. It seems to me that most other people have more friends than I do.	1	2	3	4	5	6
z. I tend to focus on the present, because the future nearly always brings me problems.	1	2	3	4	5	6
aa. My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6
bb. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
cc. Being happy with myself is more important to me than having others approve of me.	1	2	3	4	5	6

1	2	3	4	5	6
Strongly Disagree	**Moderately Disagree**	**Slightly Disagree**	**Slightly Agree**	**Moderately Agree**	**Strongly Agree**

dd. I have been able to create a lifestyle for myself that is much to my liking.	**1**	**2**	**3**	**4**	**5**	**6**
ee. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	**1**	**2**	**3**	**4**	**5**	**6**
ff. Most people see me as loving and affectionate.	**1**	**2**	**3**	**4**	**5**	**6**
gg. I don't have a good sense of what it is I'm trying to accomplish in life.	**1**	**2**	**3**	**4**	**5**	**6**
hh. I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	**1**	**2**	**3**	**4**	**5**	**6**
ii. I sometimes feel as if I've done all there is to do in life.	**1**	**2**	**3**	**4**	**5**	**6**
jj. It's difficult for me to voice my opinions on controversial matters.	**1**	**2**	**3**	**4**	**5**	**6**
kk. I generally do a good job of taking care of my personal finances and affairs.	**1**	**2**	**3**	**4**	**5**	**6**
ll. There is truth to the saying you can't teach an old dog new tricks.	**1**	**2**	**3**	**4**	**5**	**6**
mm. I know I can trust my friends, and they know they can trust me.	**1**	**2**	**3**	**4**	**5**	**6**
nn. I used to set goals for myself, but that now seems like a waste of time.	**1**	**2**	**3**	**4**	**5**	**6**
oo. The past had its ups and downs, but in general, I wouldn't want to change it.	**1**	**2**	**3**	**4**	**5**	**6**
pp. In many ways, I feel disappointed about my achievements in life.	**1**	**2**	**3**	**4**	**5**	**6**

Appendix G

Open-ended Questions about Life with Chronic Illness

Please answer the following three questions. If you need more room, please feel free to attach additional paper.

(1). How have you dealt with the uncertainty of chronic illness?

(2). What advice do you have for other mothers with chronic illness and their spouse/partners?

(3). Is there anything else you would like to tell us about living with chronic illness?

Appendix H

Study Introduction Letter

Margaret Noreuil RN MS Doctoral Candidate
University of Wisconsin-Madison
School of Nursing
600 Highland Avenue
Madison, Wisconsin 53792

Dear Family,

Recently you were told about a research study by a nurse at your usual health care clinic and agreed to learn more about a research study. This letter is being sent to invite you to participate in a research study. Your participation is voluntary. The purpose of this study is to learn more about how families manage the experience of chronic illness. We hope to gain a greater understanding of the uncertainty families experience when a mother has chronic illness; how families assist each other in living with the chronic illness and how chronic illness affects the well-being of the mother with chronic illness and her spouse/partner. We're also interested in learning what you think would be helpful for other families to know in order to manage their family life when the mother has a chronic illness. This information will aid us in further development of services for families who are experiencing chronic illness.

Enclosed you will find four copies of a consent form (two for the mother and two for the spouse/partner) that describe the study in greater detail. If you decide to participate in this study, it would involve completing the enclosed questionnaires and returning them to the investigator with one signed copy of the consent form from both the mother and the spouse/partner in the enclosed self-addressed stamped envelope. Questionnaires for the mother to complete are printed on yellow paper, the spouse/partner's are printed on green. The questionnaires take approximately 20-40 minutes to complete and contain questions related to living with chronic illness. As a small token of appreciation, a check for $20.00 per family (or $10.00 for the mother or spouse/partner individually) will be mailed to you upon receiving your completed questionnaires. I know you are very busy, and I greatly appreciate your time.

If you have any questions after reading the consent form, please feel free to contact me at 608 663-2820. I will be calling you in one week for follow-up and would be happy to answer any questions you may have regarding this study. If you do not want to participate in this study, simply discard this information.

Thank you for your time.

Margaret C. Noreuil RN MS Doctoral Candidate
Principal Investigator

Appendix I

Consent Form

Research Consent Form for Mothers with Chronic Illness

Mothers with Chronic Illness and their Spouse/Partners: Uncertainty, Family Hardiness and Psychological Well-being

You are invited to participate in a research study on how families manage the experience of chronic illness. Your participation in this research is voluntary.

Purpose:

The purpose of this study is to gain a greater understanding of the uncertainty families experience when a mother has chronic illness; how families assist each other in living with the chronic illness; how chronic illness affects the well-being of the mother with chronic illness and her spouse/partner. We would also like to know what you think would be helpful for other families to know in order to manage their family life when the mother has a chronic illness. This information will aid us in further development of services for families who are experiencing chronic illness.

Why have you been selected?

You are invited to participate because you are a family in which the mother has a chronic illness and a child under the age of 18 living at home.

What would you do in this study?

If you agree to participate, you would be asked to complete five questionnaires about the uncertainty of living with chronic illness, your family's ability to manage family life, your overall well-being at this time and what further information you believe would be helpful for other families to know about living with chronic illness. We would also ask you to complete a brief questionnaire about your background and your illness (eg diagnosis, date of diagnosis). The questionnaires would take about 30-40 minutes to complete and may be completed and returned by mail using the enclosed self-addressed stamped envelope. We would like both mothers and spouse/partners to fill out these questionnaires, if possible. Questionnaires for the mother are printed on yellow paper, spouse/partners questionnaires are printed on green paper to make it easier for you to identify which questionnaires to complete. Each family member would be paid $10.00 ($10.00 mother/$10.00 spouse/partner) as a small recognition of your time and effort.

Is there any risk?

The risk is the time and inconvenience related to completing the questionnaires. In addition, completing the questionnaires may cause distress or anxiety related to answering questions about living with chronic illness. You may skip any questions.

Is there any benefit?

It is not expected that there would be any direct benefit to you. The information you would provide is important to the further development of clinical services for families living with chronic illness, which may benefit future families.

Who will receive the results of this study?

Please be assured that all information will be confidential and will not become part of your medical record at the clinic or hospital. Study results from the entire group of families that participate may be published but individual families will not be identified in any way.

What if I change my mind?

Your participation is voluntary. You can change your mind at any time during the course of the study without penalty. If you decide not to participate in the study, it will not affect your receiving care in any way.

What if I have questions?

The Principal Investigator will be calling you in one week for follow-up and to answer any questions you may have on any part of the study. Before you sign this form, please ask any questions on any part of the study that is unclear to you. More information about the rights of research subjects may be obtained by calling the clinic/hospital patient representative at 608-263-8009. You also may call Margaret Noreuil, the Principal Investigator at 608-663-2820. We will attempt to answer any questions you may have prior to, during, or after this study.

Research Consent Form for Spouse/Partner of a Mother with Chronic Illness

Mothers with Chronic Illness and their Spouse/Partners: Uncertainty, Family Hardiness and Psychological Well-being

You are invited to participate in a research study on how families manage the experience of chronic illness. Your participation in this research is voluntary.

Purpose:

The purpose of this study is to gain a greater understanding of the uncertainty families experience when a mother has chronic illness; how families assist each other in living with the chronic illness; how chronic illness affects the well-being of the mother with chronic illness and her spouse/partner. We would also like to know what you think would be helpful for other families to know in order to manage their family life when the mother has a chronic illness. This information will aid us in further development of services for families who are experiencing chronic illness.

Why have you been selected?

You are invited to participate because you are a family in which the mother has a chronic illness and a child under the age of 18 living at home.

What would you do in this study?

If you agree to participate, you would be asked to complete five questionnaires about the uncertainty of living with chronic illness, your family's ability to manage family life, your overall well-being at this time and what further information you believe would be helpful for other families to know about living with chronic illness. We would also ask you to complete a brief questionnaire about your background. The questionnaires would take about 30 minutes to complete and may be completed and returned by mail using the enclosed self-addressed stamped envelope. We would like both mothers and spouse/partners to fill out these questionnaires, if possible. Questionnaires for the mother are printed on yellow paper, spouse/partners questionnaires are printed on green paper to make it easier for you to identify which questionnaires to complete. Each family member would be paid $10.00 ($10.00 mother/$10.00 spouse/partner) as a small recognition of your time and effort.

Is there any risk?

The risk is the time and inconvenience related to completing the questionnaires. In addition, completing the questionnaires may cause distress or anxiety related to answering questions about living with chronic illness. You may skip any questions.

Is there any benefit?

It is not expected that there would be any direct benefit to you. The information you would provide is important to the further development of clinical services for families living with chronic illness, which may benefit future families.

Who will receive the results of this study?

Please be assured that all information will be confidential and will not become part of any medical record at the clinic or hospital. Study results from the entire group of families that participate may be published but individual families will not be identified in any way.

What if I change my mind?

Your participation is voluntary. You can change your mind at any time during the course of the study without penalty. If you decide not to participate in the study, it will not affect your receiving care in any way.

What if I have questions?

The Principal Investigator will be calling you in one week for follow-up and to answer any questions you may have on any part of the study. Before you sign this form, please ask any questions on any part of the study that is unclear to you. More information about the rights of research subjects may be obtained by calling the clinic/hospital patient representative at 608-263-8009. You also may call Margaret Noreuil, the Principal Investigator at 608-663-2820. We will attempt to answer any questions you may have prior to, during, or after this study.

I have read the above and:

__________I have decided to participate;

please call me at __________________________(area code and phone Number).

The best time to call is ______________________________________

__________I need more information about the study.

Please call me at __________________________(area code and phone Number).

The best time to call is ______________________________________

AUTHORIZATION: (SPOUSE/PARTNER)

I, ______________________________________, have read the above and agree to participate in the research study described above. My signature also indicates that I have received a copy of this consent form.

______________________________________ Signature	__________ Date
______________________________________ Margaret C. Noreuil RN MS Principal Investigator	Telephone 608 663-2820

Appendix J

Approval from the Human Subjects Committee

UNIVERSITY OF
WISCONSIN
MADISON

APPROVAL NOTICE

May 11, 2001

Margaret C. Noreuil, RN, MS
K6/155 CSC

RE: **HSC Protocol #2001-169, "Mothers with Chronic Illness and Their Spouse/Partner: Uncertainty, Family Hardiness and Psychological Well-being"**

Dear Dr. Noreuil:

The Health Sciences Human Subjects Committee initially reviewed your research protocol at its March 19, 2001 meeting and requested modifications. Your response letter received on 5/10/01 and revised consents dated 5/9/01 has addressed its concerns. You may now begin your research and enroll subjects. The HSC approval for your research is for one year and will expire on March 18, 2002.

Please be sure to do the following:

- Use your HSC research protocol number (listed above) on any documents or correspondence with us concerning your research protocol.
- Keep a copy of this approval letter with your research files.
- Use only copies of the enclosed consent forms, which have the HSC approval and expiration date-stamp, to obtain informed consent; give all subjects a copy of the signed consent form.
- Comply with all requirements listed on the attached sheet, **"Investigator Responsibilities Related to the Protection of Human Subjects"**.

If you have any questions, please contact the HSC office staff at 263-2362.

Sincerely,

Elizabeth A. Schumacher-Comello
Acting Director
Health Sciences Human Subjects Committee

Enclosure: Investigator Responsibilities Related to the Protection of Human Subjects
UW Consent for Mothers with Chronic Illness dated 5/9/01
UW Consent for Spouse/Partner of a Mother with Chronic Illness dated 5/9/01

2/99

UNIVERSITY OF
WISCONSIN
MADISON

APPROVAL NOTICE

March 19, 2002

Margaret C. Noreuil, RN, MS
K6/155 CSC

RE: HSC Protocol #2001-169, "Mothers with Chronic Illness and Their Spouse/Partner: Uncertainty, Family Hardiness and Psychological Well-being"

Dear Ms. Noreuil:

The Health Sciences Human Subjects Committee reviewed and approved your Protocol Progress Report at its March 18, 2002 meeting. You may continue your research and enroll subjects. The HSC approval for your research is for one year and will expire on March 17, 2003.

Please be sure to do the following:

- Use your HSC research protocol number (listed above) on any documents or correspondence with us concerning your research protocol.
- Keep a copy of this approval letter with your research files.
- Use only copies of the enclosed consent forms, which have the HSC approval and expiration date-stamp, to obtain informed consent; give all subjects a copy of the signed consent form.
- Comply with all requirements listed on the attached sheet, **"Investigator Responsibilities Related to the Protection of Human Subjects"**.

If you have any questions, please contact the HSC office staff at 263-2362.

Sincerely,

Nichelle L. Cobb
Administrative Program Specialist
Health Sciences Human Subjects Committee Office

Enclosures: Investigator Responsibilities Related to the Protection of Human Subjects
UW Consent Form for Mothers, Version Date: 3/18/02
UW Consent Form for Spouses, Version Date: 3/18/02

7/00

LETTER OF APPROVAL

DATE: 5/9/02

MERITER IRB NUMBER: 2001-001
TITLE: Mothers with Chronic Illness and Their Spouse/Partner: Uncertainty, Family Hardiness and Psychological Well-Being
PRINCIPAL INVESTIGATOR: Margaret Noreuil, RN

EXPIRATION DATE: 5/8/03

Meriter Hospital, Inc.
nstitutional Review Board
7 North
202 South Park Street
Madison, WI 53715
08 267-6411

Dear Ms. Noreuil:

Meriter IRB met on May 8, 2002. The Board voted to re-approve the above named Protocol, and Volunteer/Patient Information and Consent Form.

No modification to the protocol or related materials is being requested.

Your ongoing responsibility to the Meriter Institutional Review Board is as follows:

- Any changes to the approved protocol and/or related materials must be submitted for IRB approval before instituting those changes. Changes to eliminate immediate hazards to human subjects may be made prior to IRB approval.
- IRB requires Continuing Review at least annually of all approved protocols. As long as your research continues, you will submit a progress report for protocol re-approval prior to your expiration date.
- When a protocol is completed or terminated a final report of your findings or a written report of termination is submitted to the IRB Office.
- All Serious and Unexpected Adverse Events in studies involving human subjects must be reported verbally within 24 hours of when the event is first recognized to the IRB Chairperson/designee and the to the IRB in writing within three working days of when the even is first recognized.

If you have questions, concerns, or requests for more information please contact me at 267-6411. *Please reference your Meriter IRB number in all communication about this protocol.*

Sincerely,

Liz Michaels, IRB Coordinator

Meriter Hospital's assurance number is T3710.

May 29, 2001

Margaret Noreuil

Dear Margaret:

On May 9, 2001, the Meriter Hospital Institutional Review Board reviewed the protocol "Mothers with Chronic Illness and their Spouse/Partner: Uncertainty, Family Hardiness and Psychological Well-being" and requested changes in the consent form. These revisions were received by Dr. Greer and he has officially approved the protocol on behalf of the IRB.

As the guidelines indicate, the IRB requires an annual progress report and annual reapproval as long as your research continues. A final report of your findings is required upon completion, and the IRB Office must be notified in the event a project is terminated. If an unexpected or adverse reaction develops in the course of the study on human subjects, you must notify the IRB Office in writing.

We wish you well with the study.

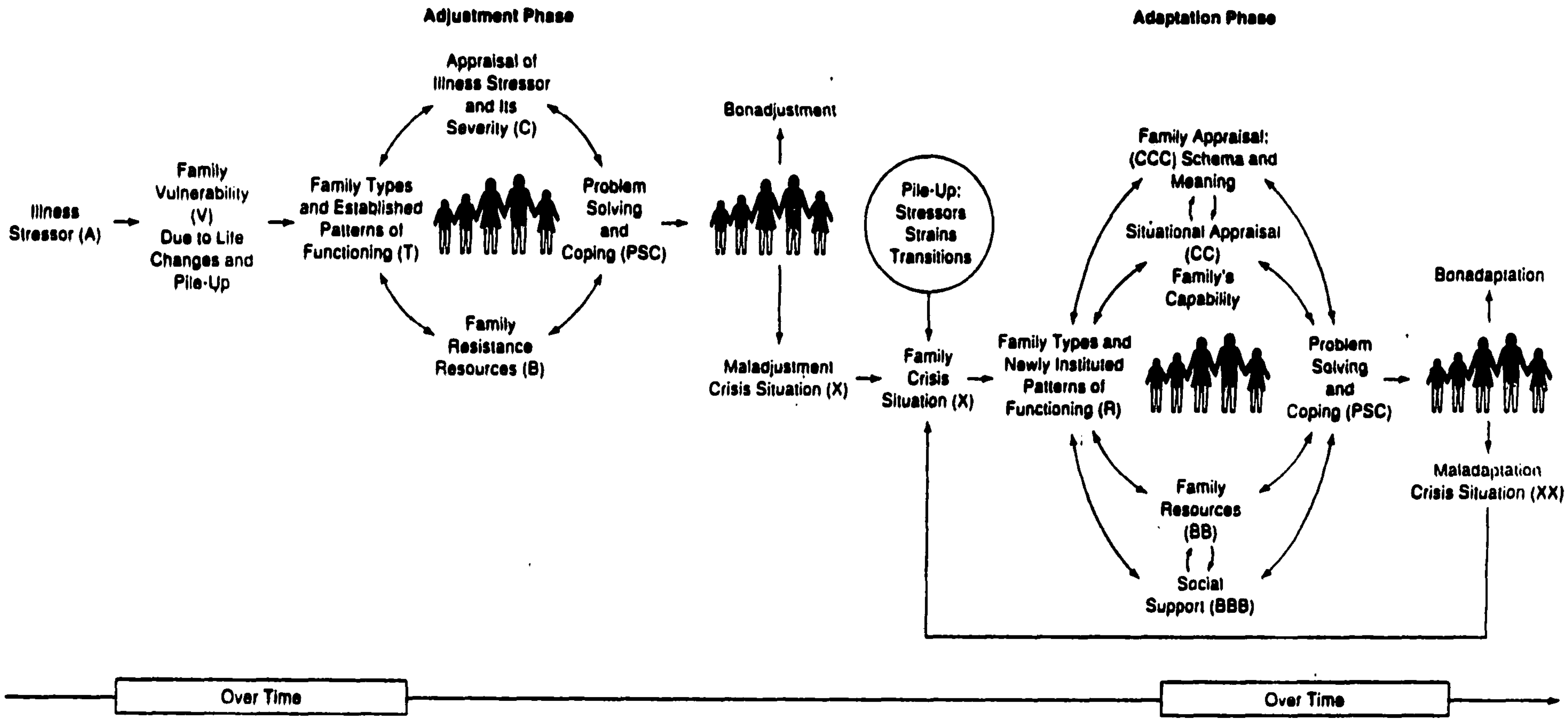
Sincerely,

Rebecca Hayter
Administrative Assistant

Meriter Hospital's assurance number is T3710.

Figure 1

The Resiliency Model of Stress, Adjustment and Adaptation



The Resiliency Model of Family Stress, Adjustment, and Adaptation. *(From McCubbin, M. & McCubbin, H. (1993). Families coping with illness: The Resiliency Model of Family Stress, Adjustment, and Adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fry, Families, health and illness (pp. 21–63). St. Louis: Mosby.)*