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Marie M. Duryea

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**MOTHERS WITH CHRONIC PHYSICAL ILLNESS AND THE
PARENTIFICATION OF THEIR CHILDREN**

BY

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B.S., Home Economics, Syracuse University, 1972
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DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy

Family Studies

The University of New Mexico
Albuquerque, New Mexico

December, 2007

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DEDICATION

This dissertation is dedicated in loving memory to my parents, Joseph and Erma Malnati. Your unending passion for learning, deep appreciation of education, and continual quest for knowledge has been passed on to me. I only wish that you both had been allowed to seek your educational dreams the way that you encouraged me to achieve mine.

I also dedicate this dissertation to my husband, Bob. Without you, this “tome” never would have been completed. Your unwavering love, never-ending faith in my abilities, and unfaltering support kept me going when times were bleak. So often this dissertation was my “partner” and took precedence over “us”, yet you never complained – not once. Thank you for helping me achieve my one and only impossible dream.

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“Virtually every great accomplishment or movement was started by someone who believed passionately in something – and someone who believed passionately in that person.” (Margaret Warren – author). I want to thank all of you for believing in me.

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ABSTRACT

More than 133 million Americans are living with chronic conditions and this number continues to rise (Partnership for Solutions, 2004); by 2020, it is estimated that 157 million people will suffer from chronic illnesses (Anderson, 2003), a large percentage of whom are in their child-rearing stage of life.

Incorporating concepts from family systems and family development theories, this exploratory study examined the impact of maternal chronic physical illness on children. Specifically, it examined the extent to which length of illness and symptom severity of fibromyalgia and rheumatoid arthritis; mother's age, educational level, and marital status; perceived effects of the illness on parent, child, and parent-child interactions; and parent and child's perceived availability of and satisfaction with support are related to the child's parentification.

Two-hundred mothers and their oldest child, aged 11-17 years, answered the researcher-developed questionnaire that had been mailed to them; youths also completed the Parentification Questionnaire – Youth. Results indicated that parentification was

greater for older children, females more than males, and boys whose mothers had the illness longer. Higher parentification scores also were obtained by children whose mothers reported lower satisfaction with support and who felt more burdened by their illness. Lower parentification scores were obtained by children who reported greater satisfaction with their support, said that they felt closer to their mothers, and whose mothers reported that they felt closer to their children.

Implications of these findings for preventative strategies and intervention are discussed and suggestions for future research presented. To date, little attention has been paid to the impact of mothers' chronic illness on their children. This study suggests that to reduce parentification in children whose mothers are chronically ill, increased support needs to be offered at all levels of the family system - the mother, the child, the mother-child dyad, and the family as a whole.

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CHAPTER 1

INTRODUCTION

The purpose of this chapter is to provide a general overview of the area of study to be investigated, present the two theoretical frameworks (family systems and family development) to be used in this research, briefly describe chronic illness and the importance of this topic to family studies, and introduce the research questions that were studied. A list of pertinent definitions also is provided.

Background

More than 133 million Americans are living with chronic illnesses and this number continues to rise (Partnership for Solutions, 2004). By 2020, it is estimated that 157 million people will suffer from chronic illnesses (Anderson, 2003). Part of this is due to the changing nature of illness. At the beginning of this century, people frequently died from infectious diseases and parasites. With improved sanitation, living conditions, nutrition, and medical technology, people now are living longer and are able to survive illnesses that previously would have caused them to die (Partnership for Solutions, 2004; Thorne, 1993). However, increased longevity brings an increase in the amount of chronic illnesses such as arthritis, asthma, Alzheimer's disease, cardiac conditions, diabetes, obesity, and liver diseases (Fierro, 2006).

Although chronic illnesses are not considered to be terminal, they are long-term or permanent without a cure. Often there are alternating cycles of remissions and flare-ups which produce a feeling of continual uncertainty in both ill individuals and their families. However, severe chronic illnesses have claimed many lives. In 1994, approximately 35% of all deaths between the ages of 25 and 44 occurred as a result of chronic illnesses such as heart problems, chronic liver disease, and diabetes (Armistead, Klein, & Forehand, 1995;

Steele, Tripp, Kotchick, Summers, & Forehand, 1997). A large percentage of people in this age bracket are in their child-rearing stage of life. Therefore, many children, during their critical developmental years, may be living with chronically ill parents and coping with the stresses related to parental illness (Anderson & Smith, 2007; Worsham, Compas, & Ey, 1997).

It has been suggested that when mothers are diagnosed with a chronic illness, they report a deep sense of loss and may suffer from depression and anxiety. They often question their ability to parent (Allaire, 1988; Milbrand, 2006; Thorne, 1990). Maternal chronic illness also has been associated with children's depression, substance abuse, internalization of problems, and somatic symptomatology (Brody, Flor, Hollett-Wright, McCoy, & Donovan, 1999; Fisher & Chalder, 2003; Frankel & Harmon, 1996; Hamilton, Jones, & Hammen, 1993; Jacob & Johnson, 1997; Keller et al., 1986; Steele, Forehand, & Armistead, 1997). Children with chronically ill mothers may express anger or fear of being abandoned. Sometimes they suffer from physical or emotional neglect (Brenner, 1984). When parental illness coincides with a child's adolescent development, the child may struggle with typical developmental issues as well as problems produced by having an ill parent.

To provide stability for their families, children may be forced to assume inappropriate and premature adult roles before they are developmentally or emotionally able. This process is known as parentification. Concerns have been raised that parentification can jeopardize children's health and development and produce long-term effects that reach into adulthood (Bellow, Boris, Larieu, Lewis, & Elliot, 2005; Earley & Cushway, 2002; Stein, Riedel, & Rotheram-Borus, 1999).

Conceptual Framework

Two current theories (i.e., family systems and family development) appear especially

relevant to supporting this research project. According to family systems theory, families are interacting, self-regulating entities that are composed of smaller units called subsystems. Families can contain marital (spousal), parental, and sibling subsystems (Klein & White, 1996). Each subsystem shares a unique level of interdependence along with relationship boundaries (Whitchurch & Constantine, 1993). Family members often are dependent on each other for financial, psychological, and emotional support. Consequently, any event that significantly affects an individual family member also will affect all remaining members who identify themselves as part of the family system. The relational boundaries that existed between parent and child in maintaining family functioning prior to an unexpected illness may become altered when the parent becomes ill. The child may assume his or her parent's roles and responsibilities to compensate for the parent's inability to meet the demands of the family. On a broader level, the theory's concept of hierarchy of systems denotes that families are part of larger units such as kinship groups, communities, and the larger society (Whitchurch & Constantine, 1993). A society's acceptance or rejection of chronically ill people affects not only that individual family member, but the entire family unit. Chronic illness experienced by a mother thus becomes a multilevel challenge for the entire family and for each of the subsystems as well.

Over the years, family development theory has evolved from a focus on family life-cycle stages to the study of changes in family structure and interrelationships. A primary emphasis of family development theory is an acknowledgement of a change in family dynamics with the occurrence of transitions. Using this theory, several levels of family analysis can be conducted - individual, dyadic, group, and societal (Rodgers & White, 1993). Several basic concepts used in family development theory are norms, roles, stages, events, developmental tasks, and transitions. The long-term course of chronic physical

illness experienced by a parent is likely to create continuing demands and changes within the family. When a mother is chronically ill, the burden of family care could result in a prolonged reversal of roles for the child as he or she tries to cope with adult tasks and mounting emotional stress.

Thus, the above two frameworks will be used to guide this study. Specifically, concepts from these theories, such as processes occurring in the parent-child subsystem and the nature of the roles and tasks of adolescents within the family, will be studied.

Statement of the Problem

In the past decade, research has shown that chronic illness of a family member affects the entire family system. Studies that have been conducted have focused on the family as a unit, the chronically ill individual, and/or the spouse of the ill member. However, there is a limited amount of material on children of parents with chronic illness. Information on children living with chronically ill parents - specifically those with physical illnesses - is almost nonexistent. Most of the research pertaining to parental illness and child or family functioning has investigated aspects of mental health. A gap in research on maternal chronic physical illness and child functioning exists. In August, 2007, a literature search (First Search – ArticleFirst and Medline) detected 27,312 articles pertaining to chronic illness. Of these, 1,895 pertained to women and chronic illness and of these, 293 pertained to mothers and chronic illness. Of these 293 articles, the majority were concerned with chronic mental illness or how mothers deal with their child's chronic illness. When investigating chronic illness with reference to parents and its effect on the functioning of children, two topics usually were presented - the roles of mothers in caring for chronically ill children or the experience of adult children caring for their elderly parents. There is a scarcity of research on the effects of chronic physical illness of mothers on their young children and adolescents.

Within the past century, the role of mothers in the United States has evolved from primarily that of housewife/caregiver to one of multiple roles. In our current society, “mothers are increasingly less likely to stay at home with their children, and more likely to enter the workforce and to be single parents” (Bernstein, 2001, p. 173). However, they still are generally seen as the traditional caregivers of children. When mothers become chronically ill, the stresses of juggling employment, parenting, and home responsibilities are elevated (Bernstein, 2001). To provide some relief, children may be asked to assume new or additional responsibilities. Temporary assumption of parental duties by children is part of normal family functioning. However, “when parental needs do not allow the child to focus on the developmental tasks of childhood, the process of parentification can take place” (Lazicki-Puddy, 2001, p. 3). If this process continues for an extended period of time or becomes the normal routine, it is viewed as detrimental to the child.

There is scarce research on maternal chronic physical illness and the parentification of children. An August 2007 literature search in ArticleFirst, Medline, PsychInfo, and CINAHL for the term “parentification” as part of a title (and, therefore, an apparent central focus of a study) yielded 23 items. Of these, many articles described clinical observations, evaluations, and treatment of parentification (Betchen, 1996; Carroll & Robinson, 2000; Chase, Deming, & Wells, 1998; DiCaccavo, 2006; Earley & Cushway, 2002; Hazen, Jacobvitz, & McFarland, 2005; Wells & Jones, 2000). Several articles described parentification of children with divorced, workaholic, alcoholic, or substance-abusing parents (Burnett, Jones, Bliwise, & Ross, 2006; Carroll & Robinson, 2000; Chase et al., 1998; Godsall, Jurkovic, Emshoff, Anderson, & Stanwyck, 2004; Jurkovic, Thirkiel, & Morrell, 2001; Kelley et al., 2007; Martin, 1996; Risman, 2002; Robinson & Chase, 2001; Schimming, 2001; Shifflett & Cummings, 1999; Teyber, 2001; Veronie & Fruehstorfer, 2001; Walker, 2001).

There were two articles that specifically referred to the concept of parentification in the title and pertained to physical illness. One article (Lackey & Gates, 2001) focused on adults who, as children, had cared for chronic physically ill parents and the other article (Stein et al., 1999) described adolescent parentification when living with parents with AIDS. Neither of these studies addressed the relationship between chronic physical illness of mothers and parentification of their children. At this time, as far as this researcher knows, there have been no studies investigating mothers' chronic physical illness and the extent of parentification of their children. Given the increasingly high incidence of chronic disease and its differing presentation (as opposed to acute or terminal disease), it is important that we examine its impact on children in terms of parentification. Also, to add to what is already known about correlates of parentification, and thereby provide suggestions for preventative strategies, factors that may act as a buffer against parentification also need to be examined.

Research Questions

Thus, this study concentrated on mothers who have a non-terminal, cyclic, chronic physical illness - rheumatoid arthritis and/or fibromyalgia - and investigated (a) the extent to which parentification of their pre-adolescent and early adolescent children occurs during the flare-ups and remissions associated with this disease, and (b) the influence of selected variables on that effect. Specifically, for pre-adolescents and early adolescents, did their mothers' chronic physical illness affect their family roles and responsibilities? And, did the extent of that effect vary in relation to selected background characteristics of the mother and child as well as characteristics of the mother's disease? A review of the research literature indicates that influences such as mother's age, educational level, number of children in the household, and marital status as well as the child's age and gender are related to parenting differences in adolescence (Hamner & Turner, 2001) as well as to

“increased or decreased opportunities for children to become parental or parentified children” (Winton, 2003, p. 61).

Accordingly, the researcher examined various factors that may contribute to the extent of parentification associated with the mother’s chronic physical illness such as maternal background characteristics (e.g., age, educational level, employment status, marital status, and number of children); characteristics of the illness (e.g., age at onset, length of illness, and severity of symptoms); adolescent background characteristics (e.g., age, employment status, gender); and affective-social variables such as level of illness burden and perceived availability and satisfaction with sources of support as reported by both the mother and youth. Also, a detailed description of the youth’s family responsibilities (i.e., the nature of the roles and responsibilities that they may assume such as household tasks, caring for siblings, and disease-related caregiving of the mother), and the similarity of perceived positive and negative aspects of the disease by mothers and their children were studied.

When reviewing the literature for variables associated with the experience of fibromyalgia and rheumatoid arthritis that might be related to the extent of parentification, educational level, severity of illness, social support and past parentification of mothers were found to have been identified in the literature as being important. Low educational level has been found to be related to the severity of both illnesses (Brekke, Hjortdahl, & Kvien, 2003; Eberhardt & Fex, 1995; Pincus & Callahan, 1993; Young, 1992; Verbrugge, Gates, & Ike, 1991; Vliet Vlieland et al., 1994). Social support has been associated with decreased pain and improved adherence to medical regimens (Evers, Kraaimaat, Geenen, & Bijlsma, 1998; Keefe, Affleck, et al., 1997; Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004). Parentified mothers are more likely to parentify their children through intergenerational perpetuation of parentification (Robinson, 1999). Given these potential associations, it appeared promising to further investigate these variables and their

relationship to the extent of parentification of ill mothers' children.

Specifically, the following research questions were addressed:

1A. Do children's scores on the PQ-Y differ significantly by the child's age?

1B. Do children's scores on the PQ-Y differ significantly by the child's sex?

2A. Are children's scores on the Parentification Questionnaire - Youth (PQ-Y) (Godsall & Jurkovic, 1995) significantly related to their mothers' length of illness, severity of the symptoms, and cyclic nature of her rheumatoid arthritis or fibromyalgia as reported on the Parent Questionnaire?

2B. Does this relationship differ significantly according to the child's age or sex?

3A. Are children's scores on the PQ-Y significantly related to their mothers' educational level, age, or marital status as reported on the Parent Questionnaire?

3B. Does this relationship differ significantly according to the child's age or sex?

4A. Are children's scores on the PQ-Y significantly related to their mothers' perceptions of availability of satisfactory sources of support as reported on the Parent Questionnaire?

4B. Does this relationship differ significantly according to the child's age or sex?

Definition of Terms

Chronic illness. Chronic illness is a long-term illness, permanent disability, or disease that is treatable but not curable and interferes with the person's normal physical, psychological, and/or social functioning. It is characterized by relatively stable periods of time that are interrupted by periods of acute episodes of illness which may require medical attention (Braden, 1993; Campbell, 2002; Zarski, West, DePompei, & Hall, 1988).

Fibromyalgia. Fibromyalgia is defined as a chronic illness exhibiting widespread body pain and extreme fatigue (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2004a).

Parental child. A child who acts as parent to their sibling(s) (Winton, 2003).

Parentification. Parentification is defined as a situation in which children assume the roles and responsibilities of their parent(s) and has been categorized as: a) expressive or emotional, providing emotional caregiving of parents by their children; b) instrumental, providing physical caregiving by children to their parents; and c) intergenerational or transgenerational, comprising two or more generations of parentification in one family (Chase, 1999; Jurkovic, 1997).

Parentified child. A child who acts as a parent to his or her own parent(s) (Winton, 2003).

Rheumatoid arthritis. Rheumatoid arthritis is defined as a chronic systemic disease characterized by inflammation and progressive deformity of the joints (King, 2003). Pain and swelling of joints with resulting limited bodily movement accompany this illness.

Social support. Social support refers to interpersonal relationships with specific groups or people such as family, friends, neighbors, professionals, and/or clergy who furnish assistance during times of need (Cigrang, Hryshko-Mullen, & Peterson, 2003; Lackner, 1999; Parker & Wright, 1997; Primomo, Yates, & Woods, 1990; Wills & Fegan, 2001).

Social network. Social networks consist of individuals or groups of people (i.e., family, friends, neighbors, professionals, clergy) who provide social support (Fyrand, Moum, Finset, & Glennas, 2002).

Justification

It is hoped that findings from this study will provide new information regarding mothers with fibromyalgia and rheumatoid arthritis (both chronic, physical illnesses) and the extent and type of parentification that occurs in their families. Furthermore, this research attempted to discover what factors may help to reduce any potential negative effects from extensive parentification.

Chapter 2

REVIEW OF LITERATURE

This chapter provides background information and describes the findings from current research on those variables and concepts that are germane to this study - chronic illness, in general, rheumatoid arthritis and fibromyalgia specifically, and parentification. A historical perspective of chronic illness is presented, including the development of its definition and evolving social acceptance. Pertinent details of the chronic illness experience, particularly maternal chronic illness, mother-child relationships, and adolescent adjustment are provided. A description of rheumatoid arthritis and fibromyalgia (the illnesses specified for this study), including their incidence, symptoms, diagnosis, treatment, prognosis, and correlates follows. Concepts from two theoretical frameworks (family systems and family development) are introduced as they are seen to apply to chronic illness. This is followed by a discussion of parentification encompassing its history, definition, and factors influencing its occurrence and impact as suggested in current research. The chapter concludes with a summary of the information provided, thereby leading to the questions being posed by this research.

History and Definition of Chronic Illness

Historical Perspectives

Throughout the recorded history of all cultures and societies, special attention always has been provided to the sick and disabled. Whether this attention is positive or negative depends on how society views their ill members, and in turn, how chronically ill individuals view themselves. Many ill individuals have had to adapt to their illness within a social climate that frequently is far from supportive (Gordon, Feldman, & Crose, 1998; Schilling, 1981).

Society is the larger economic, political, and social system under which other systems such as the individual, family, and community function. “[C]hronic conditions have a significant measurable impact on the community and the society in which the individual lives, and in turn, that society has an effect on the chronically ill person” (Grey, 1992, p. 82). According to Dimond and Jones (1983), society’s acceptance or rejection of chronically ill people is based on several factors which influence its response to illness:

1. Society’s beliefs about the origin of the disability or illness. If people are thought to be ill because of something they have or have not done (e.g., committed sins, social inferiority), society considers them to be outcasts and ostracizes them. If illnesses are attributed to natural causes beyond the control of people, then society attempts to help these people during their illness and suffering. Our current society reflects an amalgamation of both perspectives.

2. Society’s present socioeconomic status and rate of unemployment. When economic survival depends on healthy workers, society is likely to develop a negative view of their ill members. In technologically advanced societies, less physically and mentally competent people still can be contributing members. Yet in the United States, there also is a firmly embedded functionalistic work ethic that fosters prejudicial treatment of less competent people.

3. Society’s beliefs about the origins of poverty and the government’s role in its alleviation. When laziness, lack of motivation, or immorality is attributed to causing poverty, society is reluctant to intervene. “Disabled people (usually poor) either have been left to shift for themselves or have been rounded up and placed in institutions funded by the government for the purpose of reforming and training” (Dimond & Jones, 1983, p. 32). This was a prevalent practice in the seventeenth and eighteenth centuries.

4. Degree of illness stigma. This depends on the type of illness; body parts affected;

whether the illness is emotional or physical, curable or incurable, visible or invisible; and the extent to which ill people embarrass or create discomfort in others. Chronically ill people are stigmatized because, in some way, they are different from people who are designated as normal (Joachim & Acorn, 2000; Royer, 1995).

5. Lobbying efforts and media coverage. At the conclusion of World War I, veterans' groups participated in large-scale actions to lobby for rehabilitation and integration back into society. They were successful in obtaining special opportunities and privileges. However, nations only support specialized programs for disabilities if they feel the situation has merit. In the United States, veterans returning from the unpopular Vietnam War were treated with much less gratitude and respect than veterans returning from more popular wars.

Currently, our society in general values people who are productive, rugged individuals as well as people who are beautiful, strong, and youthful. Those who do not meet these values often are considered to be economic and social burdens. People with chronic illnesses frequently have a reduced capacity to work. Therefore, the public has a less favorable view of the value of chronically ill people (Schilling, 1981).

In addition, media portrayal of people with specific illnesses creates and/or enhances societal impressions. Public awareness of disabilities increased with the March of Dimes (polio). It now includes numerous other conditions. While public awareness of people's illnesses and disabilities affects society's acceptance of them, it does not necessarily affect the way these people are individually perceived in social settings. This is contingent on the definitions and labels assigned to the illness and to the individual.

Development of Chronic Illness Definition

Medical

In the 1920's, the United States became concerned about the increase of chronic illness

and disability and the ensuing social and economic costs (Anderson & Bauwens, 1981). During the economic depression of the late 1930's and into the 1940's, our country realized that there was a need for a national program to deal with chronic health problems. In 1947, the American Hospital Association, the American Medical Association, the American Public Health Association, and the American Public Welfare Association issued a joint statement advising that prevention should be considered the basic approach to chronic illness. This spurred the formation of the National Commission on Chronic Illness in 1949 (Anderson & Bauwens, 1981).

In 1956, this commission issued a classic definition for chronic illness that still is in use today. This definition states that chronic illness is “any impairment or deviation from normal that has one or more of the following characteristics: it is permanent; leaves residual disability; is caused by a nonreversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care” (Anderson & Bauwens, 1981, p.3). This definition was based on a medical model that emphasized people's needs created by physical illness and caregiving roles. Illness over a period of time was an important feature of this definition of chronic illness.

During the 1970's, definitions of chronic illness still emphasized physical pathology and excluded mental illness. However, chronic illness was viewed in relation to how it affected the whole person as opposed to specific diseases or body parts (Donnelly, 1993).

In the early 1980's, chronic illness definitions broadened to include mental illness as well as physical illness. It was acknowledged that chronically ill people could not be cured, required supportive care, and needed to assume self- responsibility. Expanded health-care roles of families and patients were encouraged. Other professions, in addition to physicians, took part in planning and caring for the chronically ill.

During the 1980's, the focus of chronic illness was on "specific concepts (e.g., reconstitution of self; family intervention) in specific populations (e.g., children) rather than the totality of the experience" (Thorne & Paterson, 1998, p. 173). The use of individually-focused frameworks to view chronic illness gave way to focusing on the broader impact of chronic illness on families and societies (Armistead et al., 1995; Lewis, Hammond, & Woods, 1993). By the end of the decade, developmental and family systems perspectives were being applied to chronic illness. This new format produced complex models for understanding chronic conditions. Rolland (1987a) developed a model of chronic illness which included dimensions of illness - onset, course, outcome, and degree of incapacitation caused by the illness. This model focused on the "relationships among the progression of the illness and the individual's and family's development and responses" (Donnelly, 1993, p. 3). It has been used to explore systems created by the interaction of chronic illness with individuals, families, and other biopsychosocial systems (Collier, 1990).

Individual or Personal Definition

Individuals define themselves - not just by age, body appearance, behavior, values, and social class - but as other people perceive them (Steinmetz, Clavan, & Stein, 1990). Chronically ill people respond not only to the way their family, friends, and health care and social service providers see them, but they incorporate the definitions placed on them by their disabilities (Sakalys, 1997). Their personal disabilities are a function of the interaction of clinical, personal, and social definitions:

1. Clinical definition: This is an anatomical or physiological definition by which people are seen as the disease. The treatment they receive is related only to the illness or disease activity and includes medication, diet, or surgical intervention (Dimond & Jones, 1983; Schoenfeld-Smith et al., 1996).

2. Personal definition: This definition centers on the way people view themselves with the disease and the way they appraise their ability to cope with the disease. Their perspective becomes a key element in their management of the illness. This self-definition is developed from the ill person's view of her/his age, sex, culture, social role, loss of functions, changes in life style, and activity level. The way in which the illness affects people depends on the point in the life cycle when it occurred; the type and extent of the limitations; the degree of visibility and stigma attached to the disease; and the prognosis, symptoms, and treatment that is needed (Dimond & Jones, 1983; Schoenfeld-Smith et al., 1996).

3. Social definition: This definition is provided (either implicitly or explicitly) by the person's family, friends, health care providers, and society. When a person deviates from what is considered normal, others respond. As Dimond and Jones (1983) have pointed out, this action has a profound impact on the way the ill person manages the social situation.

The interactions of these three definitional systems become the major factors which determine how the person with chronic illness will behave. Therefore, the effect of chronic illness is viewed as a function of the interaction of the clinical, personal, and social definitions.

Chronic Illness Statistics

During the last century, the changing nature of illness and death has contributed to larger numbers of people living with chronic health conditions. At the beginning of the 20th century, people in the United States frequently died from infectious and parasitic diseases. These deaths often were due to limitations in medical technology and lack of public health information. With improved health care, nutrition, and advances in medical technologies, the average life expectancy continues to increase, resulting in a larger population of elderly and chronically ill.

An increase in longevity also has created a rise in the number of chronic illnesses such as arthritis, cardiac conditions, diabetes, hypertension, obesity, Alzheimer's, liver, and respiratory diseases (Robert Wood Johnson Foundation, 2006). While deaths from infectious diseases have decreased, deaths from complications arising from chronic conditions have increased. People who die from chronic illnesses usually have lived with the illness for a long period of time (Institute of Health and Aging, 1996).

Chronic illnesses have replaced infectious diseases as the leading causes of death (Navarro, Voestch, Liburd, Giles, & Collins, 2007). The chronically ill now have become the largest health care consumer population (Fierro, 2006; Stuijbergen, 1987; Thorne, 1993). In 2005, the nation's total health care cost was almost \$2.0 trillion – an average of \$6,697 per person (Catlin, Cowan, Heffler, & Washington, 2007). It is estimated that national health spending will reach \$3.1 trillion by 2012 (Heffler et al., 2003; Smith, Freeland, Heffler, & McKusick, 1998).

Currently, 133 million Americans are living with one or more chronic conditions (Partnership for Solutions, 2004). Nearly 60 million Americans live with multiple chronic illnesses. Two and one-half (2.5) million women and 750,000 men are living with five or more of these diseases (Partnership for Solutions, 2001). Future projections estimate that by 2020, there will be approximately 157 million chronically ill people (one-half of our population), with 81 million having 2 or more chronic conditions (Anderson, 2003).

“Chronic, disabling conditions cause major limitations in activity for 1 of every 10 Americans, or 30 million people” (CDC, 2003, p. 2). In 2004, arthritis and other musculoskeletal conditions were the most frequently reported cause for limiting activity among working-age adults (National Center for Health Statistics, 2006). More than \$230 billion was lost in productivity (National Institute of Nursing Research, 1997). Chronic illnesses cost businesses an estimated \$33.6 billion annually in caregivers' lost

productivity (MetLife Mature Market Institute & National Alliance for Caregiving, 2006). In 2004, approximately 28.9 million caregivers provided uncompensated care to chronically ill and disabled people at a market value of \$306 billion (Arno, 2006).

Although we have made enormous advances in improving the lives of people with chronic diseases, these conditions still account for 70% of all deaths in the United States (CDC, 2003). In 1994, approximately 40% of all deaths between the ages of 25 and 44 occurred as a result of chronic illnesses such as cancer, chronic liver disease, heart problems, and diabetes (Armistead et al., 1995; Steele, Forehand, et al., 1997; Steele, Tripp, et al., 1997).

A large percentage of people in this age bracket are in their child-rearing stage of life (Anderson & Smith, 2007). It has been estimated that while in their developmental years, as many as 5% to 15% of children and adolescents may be living with chronically ill parents (Worsham et al., 1997). And at the same time, these children are coping with the stresses related to parental illness. The psychological, physical, and economic impacts are of special concern because of their effects on children and families (Aldridge & Becker, 1999; Drotar, 1994; Mukherjee, Sloper, & Lewin, 2002; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Pedersen & Revenson, 2005).

The Chronic Illness Experience

As a society, we appear to be obsessed with health. Annually, millions of dollars are spent on health club membership fees, diet foods, visits to physicians, and pharmaceutical prescriptions. The media provides unending information on how we can attain the ideal body, live more healthy lives, and achieve a near perfect state of health (Thorne, McCormick, & Carty, 1997). The assumption of our society is that people are basically healthy; this is our normal, desired state. Yet, despite society's obsession with health, people do become ill. When this happens, these people no longer meet society's

expectations.

Illness is more than a collection of physical symptoms and signs. According to Toombs (1993), when people become ill, they experience a sense of global disorder, “a disorder which incorporates not only specific bodily dysfunction but a concurrent disruption of one’s self and of the surrounding world” (p. 223). This creates turmoil and change throughout all areas of their lives. Dekkers (2001) described the upheaval of chronic illness as follows:

Chronic physical disorders can be incapacitating due to their “nature”, that is due to problems of cognition, reality disturbances, restrictions of movement, reduced levels of energy, not to mention the demands of treatment and lack of necessary support to enable the individual to maximize his bodily functions. (p. 186)

Chronic physical illness affects all aspects of a person’s life. Problems may include physical disabilities, negative body image, restrictions in daily activities, decreased self-sufficiency, work restrictions, social stigmata, and changes in one’s sense of identity and self-esteem (Dekkers, 2001).

The changing and progressive nature of chronic illness sets it apart from other diseases. Chronically ill people do not face only one crisis at the time of diagnosis; they contend with a series of crises throughout the course of their illness. The uncertainty and unpredictability of when these episodes will occur adds to the burden of the illness. Furthermore, adjustments must repeatedly be made as the illness progresses and additional developmental changes occur in patients and their environments.

Thus, chronic illness is not static. The restructuring of one’s life caused by chronic illness is not a one-time experience (Delmar et al., 2005; Delmar et al., 2006). Over time, there are changes in the nature of the illness, developmental differences in the individual, management of the disease, sources of social support, and nature and extent of coping

strategies. Adjustments to chronic conditions must be made repeatedly as the disease changes, waxes, and wanes (Paterson, 2003). Final adjustment is never achieved. Instead, chronically ill people are continually in the process of accommodating to change and this process is never completed (Altschuler, Dale, & Byng-Hall, 1997; Anderson, Blue, & Lau, 1991; Gregg, Robertus, & Stone, 1989; Lyons, Sullivan, & Ritvo, 1995; Telford, Kralik, & Koch, 2006).

Chronic illness delivers both short- and long-term effects for people. A few of the personal areas affected by chronic illness are self-concept, emotional resources, marriage and family relationships, sexual behavior, social adjustment, career adjustment and planning, recreational and leisure activities, and financial planning (Gregg et al., 1989; Stanton, Revenson, & Tennen, 2007). Changes in functioning and appearance, major assaults on self-esteem and self-image, disruption of future plans, and disappearance of social roles also are included (Abraido-Lanza & Revenson, 2006; Devins, 2006; Eberhardt, Larsson, Nived, & Lindqvist, 2007; Heijans, De Ridder, & Bensing, 1999). Whatever the process of the disease, all chronically ill people undergo psychological struggles to understand, control, and adjust to the illness (Goodheart & Lansing, 1997; Kocaman, Kutlu, Ozkan, & Ozkan, 2007; Livneh, Martz, & Bodner, 2006).

The Nature of Chronic Illness

Illnesses can be categorized as acute, chronic, or terminal. In acute illnesses, people become sick, seek medical care and/or rest, and recover. While there is a period of disability, people can expect a cure with full resumption of normal activity. During this type of illness, people usually are relieved from the responsibilities of completing their normal duties and activities. Their primary objective is to obtain medical care where diagnosis, treatment, and cure of the illness can be achieved. There often is time off from work for being sick. Support from employers, friends, and family usually is strong. Any

impairment, loss, or changes in life are temporary. After recovery, people can resume their normal life style (Sapp, 1992).

During terminal illnesses, people become sick, seek medical care, and establish new life patterns. This type of illness is an ongoing health problem with no cure. Terminal illnesses, such as AIDS, and some cancers and heart diseases, can shorten one's life span and cause an earlier death. With terminal illnesses, there is no recovery and people never resume their previous, normal lifestyle. These expectations of loss (anticipatory loss) make it difficult for ill persons, their family, and their friends to interact (Rolland, 1999). There can be structural, emotional, and psychological alienation and isolation (Mann & Dieppe, 2006; Rolland, 1987a). Illnesses that are deemed fatal have more profound psychosocial impact than those conditions that do not result in significantly impaired health and/or death (Rolland, 1984).

Chronic illnesses are ongoing health problems. They are treatable but not curable, with their own characteristics, visibility, and prognosis. The severity may vary over time. Any changes in the methods of treatment, care, prognosis, or functioning of the patient affect every family member. These changes create stress within the individual and family because they must be managed through individual and family efforts (Zarski et al., 1988).

Learning to live with chronic health problems is a challenge. When people are diagnosed with chronic illnesses, they most likely will never be able to return to the levels of health and activity they had enjoyed prior to the onset of their illness. While some people may be granted long periods of remission over the course of their disease, most chronically ill people will be faced with continual challenges of loss of function, episodic pain, additional medical costs, inconvenient long-term medical treatment, and the "threat of more serious medical problems as their illness progresses" (Gregg et al., 1989, p. 4).

The Courses of Chronic Illness

There are three general courses of chronic illness: progressive, constant, and relapsing/episodic (Papadopoulos, 1995; Rolland, 1987a; Thorne, 1993).

Progressive Illness

In progressive illness, such as cancer, people who are not treated continually experience symptoms of the disease as it increases in severity. Family members constantly face role adaptations and new responsibilities as the disease continues. There is little relief from the demands of the illness. Continual adaptation and role changes increase strains on the family. Whether the disease progresses slowly or rapidly also determines the amount and severity of the stress that the family experiences. “The pace of adapting to ever new demands of a rapidly progressive disease mounts as the time course shortens. By contrast, a slowly progressive illness may place a higher premium on stamina rather than adaptation” (Rolland, 1987a, p. 38).

Constant Illness

In constant chronic illness, the state of a person’s health changes; there is an initial recovery; and then stability occurs over time. Examples of constant chronic illnesses are trauma resulting in amputation, stroke, blindness, or spinal cord injury with paralysis. After the initial illness event and recovery period, the person experiences a definite deficit in functioning such as paralysis, speech loss, or cognitive impairment. Yet this change is stable and predictable over a considerable time span. Initially, the family faces the person’s illness deficits and adapts to their new role changes and tasks demanded by the illness. Since the disease is constant, the family does not re-experience new role demands and tasks. Change is relatively predictable and stable over time (Papadopoulos, 1995; Rolland, 1987a).

Episodic/Relapsing Illness

In episodic or relapsing chronic illness, the person alternates between periods of a low-level illness or absence of symptoms to an exacerbation or flare up of illness. Examples of these illnesses are Crohn's disease, asthma, peptic ulcers, arthritis, fibromyalgia, and multiple sclerosis. During the stable, low-level phase, the person and family can engage in periods of "normal life". When there is a flare up, "normal life" ceases and new tasks and roles are assumed by the person and the family. It is the uncertainty of when the next recurrence will happen (and it will happen) and how long it will last that places additional, continual strain on everyone (Campbell, 1995).

This type of chronicity requires an extremely flexible family. They must be able to move back and forth between the noncrisis, stable time and the crisis, flare up time of the ill person (Patterson & Garwick, 1994). In episodic/relapsing chronic illness,

[s]train on the family system is caused by both the frequency of transitions between crisis and noncrisis, and the ongoing uncertainty of when a crisis will next occur. Also, the wide psychological discrepancy between periods of normalcy and illness is a particularly taxing feature unique to relapsing chronic illness. (Rolland, 1987a, p. 39)

Families living with chronic illness confront the same types of challenges as other families, plus there are additional demands inflicted upon them because of the illness. Financial strains, loss of family spontaneity and privacy, problems with health care providers and insurance companies, caregiving strains, worries about the future, and constant decision-making routinely need to be dealt with (Ahlstrom, 2007; Patterson & Garwick, 1998). These demands vary according to the type and nature of the illness.

Stages of Chronic Illness

One of the most pervasive facets of chronic illness is the experience of strong emotions. These emotions arise due to the sense of loss that may be experienced in

chronically ill people's lives and by a number of fears associated with chronic illness such as death, incapacitation, pain, and abandonment. Several researchers have developed or applied "stages" to chronic illness that attempt to incorporate these emotions.

Kubler-Ross' (1975) proposed stages of grief (denial/shock, anger, bargaining, depression/mourning, and acceptance) often are used to describe the process that chronically ill people follow after the initial diagnosis. (It must be emphasized that people may never experience some stages, and there is no right or wrong way to pass through them.) With each recurrence of chronic illness, the person may again feel loss. Once a person is diagnosed as chronically ill, he/she may never go back to the way he/she was. With each new session of illness, there may be further change and loss.

Kane (1991) stated that illnesses consist of three predictable phases (acute, subacute, and chronic) that are composed of emotional experiences. The acute phase of chronic illness usually occurs when people experience the initial realization that they are ill. This is often the most uncomfortable phase and it is unique to every individual. During this time, intense emotions, mood swings, disorientation, shock, confusion, and helplessness are noted. This process is perceived by Kane as meaningful and therapeutic. It is not a time for action. Instead, "[c]onsider this period as an invisible bridge between who you were and who you will soon be" (Kane, 1991, p. 38). Personal definitions are reviewed and redefined. While this phase is finite, it can recur with disease progression and remissions.

The subacute phase occurs when the emotional swings of the acute phase subside into more steady, distinguishable emotions such as depression, anxiety, fear, or anger. This is the time to act, to move forward in accepting/treating the illness. "Lingering depression can represent real grief for the loss of your former self-image" (Kane, 1991, p. 43).

Adequate support and expression can help to shorten this time period.

The chronic phase is long-term. Emotions surface and recur over longer time periods. Kane (1991) reported that the most common feeling is that of guilt. People feel remorse because the illness has disrupted their home, workplace, and social relationships and it has affected other people. Blame is another facet of this phase. People try to determine whose fault it is that they are sick. Kane suggested that instead of concentrating on the cause of the illness, people should take this opportunity to learn about themselves and change for the better.

LeMaistre (1985) also embraced this approach to illness. While traditional methods of handling illness usually are gloomy resignation or Pollyanna denial, she suggested a “wellness approach” that stresses both the experiences of loss and the responsibility to look beyond oneself to re-establish quality in life. Adaptation is the necessary key. According to LeMaistre, the whirl of emotions triggered by chronic illness can be separated into stages - crisis, isolation, anger, reconstruction, intermittent depression, and renewal. Each stage in wellness progression involves acknowledgement of internal pain, loss, and grief. Also, the order of the stages of illness can vary and may be repeated as symptoms return or include additional losses.

The Emotional Impact of Chronic Illness

Sense of Loss

Chronic illness creates emotional trauma due to the loss of a valued level of functioning. “The chronically ill person not only suffers the loss of immediate competency but is deprived of an expectable future” (LeMaistre, 1985, p. 17). With these losses, it is common for people to experience anger, fear, depression, grief, and anxiety (LeMaistre, 1985; Mikulincer & Florian, 1996; Primomo, 1989).

Change in any aspect of one’s life (birth, promotion, marriage, illness) may produce a sense of loss - loss of what life previously had been and what life will not be in the future.

According to George and Cristiani (1986), each loss/change, whether tangible (property or personal items) or intangible (divorce or friendship), involves a grieving process.

Therefore, when people are diagnosed with an illness, they experience physical, psychological, and social losses and grief (Kralik, van Loon, & Visentin, 2006). The losses may happen all at once or they may occur with more gradual deterioration as the chronic illness progresses. Implicit with physiological loss is “the loss of the opportunity to accomplish normal developmental tasks, ...a loss of a sense of mastery, competence, and self-esteem, ...and the actual or perceived loss of the ability and opportunity to live independently” (Patterson, 1988a, p. 91).

Boss and Couden (2002) applied the theory of ambiguous loss to chronically ill individuals and their families. Ambiguous loss is defined as “a situation where a loved one is perceived as physically present while psychologically absent, or physically absent but kept psychologically present...” (p. 1352). Chronically ill people often experience ambiguous loss because “[t]hey are here, but no longer as they once were” (Boss & Couden, 2002, p. 1352). Family members also can experience ambiguous loss when their loved one is physically present, but psychologically absent. Because the symptoms of chronic illness are cyclic, it is difficult for families to adapt to the fluctuating absence and presence of the ill person. Ambiguous loss blocks the ability of people to cope and grieve. This contributes to anxiety, hopelessness, conflict, and depression in the ill person and his/her family.

Schaefer (1995b) wrote about chronic illness as a paradox of loss and discovery. Chronically ill women have reported losses of independence, livelihood, friends, relationships, self, health, support, control, function, truth, and spontaneity. Yet, chronic illness also has provided chances for discovery of new information (particularly about the disease), control, true friends, self, a higher power, personal strength, humor, and hope.

Life with chronic illness is a paradox of opposing forces with highs and lows, loss and discovery, and good days and bad days. The art of surviving chronic illness is to learn to negotiate the roller coaster pattern of life.

Depression

Depression is a common occurrence in chronically ill people (Chapman, Perry, & Strine, 2005; Davis & Gershtein, 2003; Simon, Von Koroff, & Lin, 2005) and in those who experience chronic pain (Tennen, Affleck, & Zautra, 2006). The number of lifestyle disruptions (e.g., physical incapacitation, chronic pain, decreased stamina and strength, new medical regimens) leads to increased emotional distress. Physical disabilities, anatomical changes, and functional deficits lower people's access to positive daily experiences and decreases personal feelings of control (Devins et al., 1993). Depression occurs when there are "long duration of episodes, high rates of chronicity, relapse and recurrence, psychosocial and physical impairment... and the likelihood of recurrence is more than 50%" (Angst, 1999, p. 5). Depressive symptoms may include apathy, changes in appetite, disturbed sleep, fatigue or decreased energy, hopelessness, irritability, sadness, and thoughts of death (Kahan, Mitchell, Kemp, & Adkins, 2006).

Unfortunately, despite its high prevalence and adverse effects on people's lives, depression often is not accurately diagnosed or effectively treated (Angst, 1999; Katon & Sullivan, 1990; Stein, Cox, Afifi, Belik, & Sareen, 2006). Devins et al. (1993) found that the more people's life styles, activities, and interests were disrupted by illness, the greater the severity of depression.

Researchers agree that depression is prevalent in FM. Bazzichi et al. (2007) reported that 54% of the FM patients in their study "showed symptoms of depression, a result that is in accordance with the strong comorbidity observed between fibromyalgia and major depression" (p. 229). Several different explanations have been provided for this co-

occurring problem. In some studies (Raphael, Janal, Nayak, Schwartz, & Gallagher, 2004; Thieme, Turk, & Flor, 2004) researchers proposed that FM is associated with a high degree of depression because FM is a variant of a depressive disorder - i.e., a psychiatric disorder. However, Okifuji, Turk, & Sherman (2000) argued that not all people with FM are depressed. If FM were a variant of a depressive disorder, then the presence of depression would be near 100%. “While a lifetime history of depression has been reported in 50-70% of patients with FM, current major depression was found in only 18-36% of patients with FM” (Gur, Cevik, Nas, Sarac, & Ozen, 2006, p.71). To differentiate between FM and major depression, Fassbender, Samborsky, Kellner, Muller, & Lautenbacher (1997) suggested a simple clinical exam where tender points (found only in people with FM) are palpated. The occurrence of tender points can differentiate FM from major depression.

Additional studies suggest co-morbidity of FM and depression is related to a family history of or tendency toward alcoholism or depression (Gruber, Hudson, & Pope, 1996; Hudson, Arnold, Keck, Auchenbach, & Pope, 2004; Kassum & Patten, 2006; Katz & Kravitz, 1996; Michielsen, Van Houdenhove, Leirs, Vandebroek, & Onghena, 2006; Palomino, Nicassio, Greenberg, & Medina, 2007; Tot, Sahin, Oral, & Verimli, 2004). According to Raphael et al. (2004), people with FM and major depressive disorder “have a genetic and/or biologically mediated vulnerability to respond to stressful or traumatic events with psychological and pain-related symptoms” (p. 458). Other studies have found that depression is a reaction to living with FM (Antai-Otong, 2005; Gur et al., 2006; Herken, Gursoy, Yetkin, Virit, & Esgi, 2001; Nordahl & Stiles, 2007; Okifuji et al., 2000; Raphael et al., 2004; Robinson et al., 2004; Schaefer, 1995a). “...Living with constant widespread pain with no known pathology and no universally effective treatment may trigger depressive moods” (Okifuji et al., 2000, p. 213).

There are several areas of opposing research findings concerning depression and

rheumatoid arthritis (RA). For example, estimates of the prevalence of depression in RA patients vary greatly from 5%-46% (Dickens & Creed, 2001; Dickens, Jackson, Tomenson, Hay, & Creed, 2003; Dickens, McGowan, Clark-Carter, & Creed, 2002; DeVellis, 1995; Hawley & Wolfe, 1993; Katz & Yelin, 1993). This may be due in part to the difficulty of assessing depressive symptoms among people with chronic conditions. Insomnia and fatigue are symptoms of both depression and RA. "...[S]everal well known and widely used measures of depression, including the Minnesota Multiphasic Personality Inventory, the Beck Depression Inventory, and the Center for Epidemiologic Studies Depression Scale, are sensitive to the somatic aspects of RA, and consequently, persons with RA may be inappropriately classified as depressed" (Katz & Yelin, 1993, pp. 790-791).

There also is discrepancy as to whether the incidence of depressive disorders and symptoms in people with RA is equivalent to those found in other people with chronic diseases (approximately 20%). Barlow, Cullen, Foster, Harrison, and Wade (1999) stated that people with RA may experience depression at the same rate as people with other chronic illnesses. In a ten-year longitudinal study of people with RA, Hawley and Wolfe (1993) found that depression was not higher in RA patients as compared to those with other rheumatic disorders. "The notion that patients with RA have increased depression or are somehow more susceptible to depression is not supported by the data and should be abandoned" (Hawley & Wolfe, 1993, p. 2025). Yet, Katz and Yelin (1994) found that "there is a higher rate of depression among persons with RA" (p. 69). This finding has been supported in other research studies (Katz & Yelin, 1993; Katz & Yelin, 1995). According to Dickens and Creed (2001), "RA patients are twice as likely to suffer from depression as members of the general population" (p. 1327).

Several researchers have found that depression associated with RA often is a result of increased levels of pain and functional disability (Chaney et al., 2004; DeVellis, 1995;

Dickens & Creed, 2001; Dickens et al., 2003; Dickens et al., 2002; Katz, 1995; Katz & Alfieri, 1997; Katz & Yelin, 1993; Katz & Yelin, 1994; Katz & Yelin, 1995; Neugebauer, Katz, & Pasch, 2003; Ryan, 1999; Wolfe & Hawley, 1993). Furthermore, “depression in RA has been linked to older age, low levels of physical activity, morning stiffness, grip strength, pain, fatigue, helplessness, poor perception of health, increased use of health services, social stress, lack of support, low level of education, low income, unemployment, and chronic health conditions” (Soderlin, Hakala, & Nieminen, 2000, p. 177). In addition, Ang, Choi, Kronke, and Wolfe (2005) found that depression increases the risk of mortality in people with RA.

Anxiety

Chronically ill people frequently experience feelings of anxiety (Katon & Ciechanowski, 2002). According to Klein and Landau (1992), the anxious feeling may abate, but it seldom goes away because chronic illness is always there. Its pattern is repetitive, overlapping, and erratic. These random dosages of illnesses are likely to create high anxiety and a state of constant tension. Whereas most medical situations have a beginning, middle, and end, chronic illness does not provide the closure.

According to Strine, Chapman, Kobau, & Balluz (2005), anxiety and depression often occur together, and anxiety has been associated with a higher prevalence of other diseases such as angina, migraines, ulcers, hypertension, and thyroid. Several researchers have found comorbid anxiety and depression in FM (Armstrong et al., 2007; Ledingham, Doherty & Doherty, 1993; Kurtze & Svebak, 2005; Thieme et al., 2004). “[A]nxiety as well as depression is strongly related to the severity of fibromyalgia symptoms, with high levels of both anxiety and depression among the patients with more severe disease” (Kurtze, Gundersen, & Svebak, 1998, p. 192). Comorbidity of anxiety and depression also is prevalent with RA (Isik, Koca, Ozturk, & Mermi, 2007; VanDyke et al., 2004;

Zyrianova, Kelley, Gallagher, & McCarthy, 2006). Norman and Lang (2005) found that when anxiety is associated with chronic physical illness, there is greater impairment in functioning than with chronic illness alone.

Importance of Diagnosis

Chronic illness does not have a single onset pattern. Instead, the onset of illness can range from slow, insidious, progressive development of symptoms over a period of time to sudden, acute illness or injury from which there is not a full recovery.

For both chronically ill people and their families, it seems extremely important to be able to identify a definite point in time when the illness began. The actual medical diagnosis often is a major milestone, “a turning point in the process for becoming chronically ill” (Thorne, 1993, p. 17). The early chronic illness period, when people first enter into this experience, is built around the diagnosis process: the diagnostic testing, receiving the diagnosis, the meaning attributed to the diagnosis, and the impact of the diagnosis. Once the illness is named, the future can be planned.

The importance of having a diagnosis or a label for a person’s health problem needs to be recognized. From a medical point of view, the diagnosis (or labeling) of a disease is of primary importance because this dictates treatment planning and management of the chronic condition (Bedson, McCarney, & Croft, 2004; Rolland, 1987b). From a personal point of view, a diagnosis eliminates the unknown and provides a sense of relief, validity, and hope (Hayden, 1993; Sakalys, 1997; Schaefer, 1995b).

Nevertheless, to the patient, the diagnosis process also can be threatening, especially when it fails to discover the problem (Thorne, 1993). When ill people cannot get “health care professionals to validate the health problem by giving it a diagnosis, the patients [have] a very difficult time explaining their illness to others in their family and social worlds” (Thorne, 1993, p. 25). Sometimes the lack of a label makes it difficult for people

to feel comfortable and believe in themselves. Many patients and their families consider the diagnosis to be a critical turning point in their lives. It ends the dilemma of having no explanation or validation for their illness. It brings about acceptance and support from family, friends, co-workers, and society. People who do not receive a definite diagnosis remain in limbo and often are looked upon negatively and doubtfully by others.

This is particularly true for people with FM because this disease is not outwardly visible and it is difficult to diagnose. Women with FM have reported adverse medical encounters when trying to obtain a diagnosis for this illness. There is discordance between patients' and physicians' health perceptions (Dobkin et al., 2003; White, 2004). Patients "repeatedly find themselves being questioned and judged either to be not ill, suffering from an imaginary illness or given a psychiatric label" (Werner, Isaksen, & Malterud, 2004, p. 1036). This makes it difficult to credibly convince family members and others that their pain/illness is real and not imagined or psychological. They become labeled as lazy, crazy, weak, or hypochondriacs (Cunningham & Jillings, 2006).

Because of the lack of observable physical pathology, physicians become frustrated when caring for patients with FM complaints (Dobkin et al., 2003; Johnson & Johnson, 2006; Wainwright, Calnan, O'Neil, Winterbottom, & Watkins, 2006). According to Walker, Katon, Keegan, Gardner, & Sullivan (1997), physicians were "most frustrated with patients who had ongoing preoccupation with multiple medically unexplained physical symptoms as well as the perception of greater impact and lack of control over their illness" (p. 315).

The Nature and Influence of Social Support

Social support can have a positive influence on chronic illness management by providing a psychological buffer against stress, depression, and anxiety associated with illness (Danoff-Burg & Revenson, 2005; Fyrand, Wichstrom, Moum, Glennas, & Kvien,

1997; Heijmans et al., 1999; Huyser & Parker, 1998; Mayo Foundation for Medical Education and Research [MFMER], 2006; Penninx et al., 1997; Pollachek, 2001; Symister & Friend, 2003; Weinert, 2000; White, Richter, & Fry, 1992). Social support refers to assistance provided by social networks during times of need (Berkman, 1986; Cigrang et al., 2003; Lackner, 1999; Parker & Wright, 1997; Primomo et al., 1990; Wills & Fegan, 2001). Social networks refer to interpersonal relationships with specific groups or people such as family, friends, neighbors, professionals, and/or clergy (Fyrand et al., 2002). Social support and social networks provide “positive impact on somatic and mental health and quality of life... for patients with chronic disease” (Fyrand, Moum, Finset, & Glennas, 2003, p. 71).

Types of social support include: (1) emotional/expressive - things that people do that make one feel cared for and loved, usually non-tangible (e.g., providing positive feedback or encouragement, talking over problems), (2) instrumental - various forms of tangible help provided by people (e.g., childcare, housekeeping, money, transportation), and (3) informational (sometimes included in instrumental support) - a type of help that others provide through sharing knowledge and/or factual information (DesRosier, Catanzaro, & Piller, 1992; Gallant, 2003; Goodheart & Lansing, 1997; Hatchett, Friend, Symister, & Wadhwa, 1997; Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991; Sylvain & Talbot, 2002). Since peoples’ “experiences of illness both influence, and are influenced by, the social fabric that surrounds them” (Davison, Pennebaker, & Dickerson, 2000, p. 205), it only is natural that a new format for obtaining health information and support has developed. Recently, computers have become sources of a multitude of online support groups for people coping with illness (Weinert, Cudney, & Winters, 2005). In addition to emotional and instrumental social support, Fyrand, Moum, Finset, Wichstrom, and Glennas (2001) add the component of social companionship described as “social

interaction for mutual enjoyment” (p. 430).

The perception of adequate support is an essential factor in health outcomes and the amount of social support that people receive affects their quality of life. However, the actual type and amount of social support is less important than how the person perceives the adequacy of social support (Schoofs et al., 2004). Health outcomes may be determined more by the person’s perception of adequate social support, rather than the amount and type of support (Parker & Wright, 1997).

While increased social support may enhance one’s health and reduce stress, too much social support can increase depression and stress (Salovey, Rothman, Detweiler, & Steward, 2000; Cumsille & Epstein, 1994; Penninx et al., 1998; Treharne, Lyons, Booth, & Kitas, 2007). Specifically, receiving instrumental support has been found to be associated with an increase in depression. It may be that “depressed people receive more instrumental support because they arouse sympathy [or] ...receiving considerable instrumental support causes feelings of helplessness or dependency, both of which may cause depression” (Penninx et al., 1998, p. 556).

Effects of Chronic Illness on Mothers and Their Children

Traditionally, mothers have been stereotyped as caretakers and nurturers (Almeida, Wethington, & Chandler, 1999; Bernstein, 2001; Bigatti & Cronan, 2001; Blackford, 1998; Pedersen & Revenson, 2005). They tend to have more responsibility for their children through such activities as preparing meals, involving them in organized activities, and monitoring school and homework (Jacob & Johnson, 1997). Their roles in the family are based on a set of social rules (Almeida et al., 1999). Societal expectations of mothers as the primary caretaker of husbands, children, and aging parents lead to feelings of guilt in chronically ill mothers when they are unable to carry out these functions (Rolland, 1991; Walsh & McGoldrick, 1991). Today, mothers are less likely to stay at home with their

children and are more likely to work outside the home and be single parents. They experience increased stress by juggling home, childcare, and employee responsibilities. Adding chronic illness to these already taxing responsibilities augments stress levels. Revenson (1994) stated that “women with illness... feel a responsibility to keep the family and home intact, but at a great personal cost” (p. 128). Even when ill, women assume a disproportionate amount of the responsibility for providing nurturance and organization for the family.

Furthermore, Thorne (1990) noted that mothers with a chronic illness experience opposing role expectations. As chronically ill people, society requires that they “act normal”, vigilantly monitor their symptoms, and accommodate their life to their illness. “Those with chronic illnesses are not supposed to clutter their lives with extraneous family obligations” (Thorne, 1990, p. 218). However, as mothers, society requires that they be constantly available, entirely unselfish, and totally responsible. Clearly, these two role expectations are not compatible. Thorne (1990) found these conflicting role obligations are prevalent not only in society as a whole, but among health care professionals. She suggested that health care professionals who work with chronically ill mothers learn to guide their patients to compromises in their dichotomous, conflicting roles.

A diagnosis of chronic illness requires mothers to adopt life style changes which can be as simple as taking a daily medication or as life altering as becoming unemployed due to the inability to work. When chronic illness strikes, mothers must change behaviors which directly affect their illness, learn to live with chronic illness, redefine social and personal self-concepts, compensate for dwindling resources, manage illness symptoms, and participate in health treatments (Garrison, Norem, & Malia, 1996; Hatchett et al., 1997; Rolland, 1991; Ryan, 1992). Such changes can produce a sense of loss that may lead to mourning and grieving.

Effects on Mother-Child Relationships

“Human illness and disability occur in the context of a complicated web of interpersonal relationships” (Power, 1977, p. 70). When a mother is chronically ill, she finds it difficult to maintain her own normal role while also trying to fulfill her obligations as a parent. Physical and mental changes plus the uncertainty she experiences can affect the mother-child relationship. Typical or routine ways of relating to each other may be altered by pain, fatigue, and anxiety (Altschuler & Dale, 1999; Lewis et al., 1993; Morgan, Sanford, & Johnson, 1992). Instead of providing their children with security and nurturance, mothers may feel responsible for exposing them to grief, pain, and uncertainty. Disruptions in parenting have been associated with child conduct problems; compromised child adjustment; and antisocial, delinquent behavior (Pascoe, Stolfi, & Ormond, 2006). “Parenting practices and interactions of stressed parents with children are more likely to be hostile, irritable, coercive, and inconsistent than those of nonstressed parents” (Klein, Forehand, Armistead, & Long, 1997, p. 62).

In Zahlis and Lewis’ (1998) study, mothers with breast cancer reported that there were four major times when it was most difficult for their children to deal with their illness. These times occurred when: “(1) dealing with real or symbolic separations, (2) experiencing uncertainty at the beginning of treatment, (3) seeing their mother sick or upset, and (4) seeing marks or being reminded of their mothers’ illness” (Zahlis & Lewis, 1998, p. 30). Mothers also observed seven categories of behavior when their children were having difficult times. These children would change the way they talked (amount and content), need closeness and reassurance, retreat (withdrawn and quiet), distance themselves from the disease, check on mother, feel bad (angry, hopeless, friendless, negative), and act differently (e.g., misbehave or over-behave, difficulty at school). Unfortunately, several factors prevented these mothers from helping their children. They

did not know what to say or do; they were too involved in their own personal struggles; or they were too fatigued and ill (Zahlis & Lewis, 1998).

In their study of adolescent stress, Hartos and Power (2000) reported that adolescents feel closer, disclose more information, and talk more often to their mothers than fathers or other adults. They also seek their mothers' advice and guidance. These authors believe that typically mothers tend to spend more time with and are more involved in socializing their children. In Paulson and Sputa's 1996 study on changes in parenting across adolescence years, both adolescents and parents perceived mothers more than fathers as being more directly involved in parenting, especially with school and homework. Parental connectedness still is vital to adolescents (Resnick et al., 1997). This seems to support Thorne's (1990) study where chronically ill mothers are concerned that they are not available for their children. These concerns appear valid.

Parenting With an Illness

According to Allaire (1988) and Thorne (1990), chronically ill mothers are apprehensive about their abilities to parent. Four main issues of concern reported by Thorne (1990) are:

1. performance - The effects of illness restrict their abilities to perform certain parenting tasks. Fatigue, stamina, and mobility are common problems that interfere with them providing safe environments, appearing or acting like "normal" mothers, or preparing meals and doing housework.

2. availability - Unpredictable physical limitations and energy levels cause these chronically ill mothers to be less consistently available to their children than other healthy mothers. Not being able to participate in special occasions or being present during their children's special times is particularly difficult. These mothers worry about their inconsistent availability for their children's special events, daily needs, and permanent care.

3. dependency - Mothers explained how difficult it is for them to need to rely on their children for physical and emotional support. While they realize that their dependency is necessary because of their illness, they still are considerably concerned about being overly dependent.

4. socialization - Mothers worry about what their children are learning from dealing with the mother's chronic illness. They believe that the chronicity of illness within their homes forces children to learn in detail about sickness - more so than their peers. Over the years, mothers feel that communication is affected because the family becomes tired of hearing about illness. They worry that the continual flare ups desensitized their children to suffering around them. Yet, many mothers noted that their chronic illness heightened their children's capacity for compassion.

Chronically ill mothers worry about the quality of their parenting (Milbrand, 2006). Simons, Chao, Conger, and Elder (2001) found that "low parental control during late childhood predicted increases in affiliation with deviant peers and delinquency during adolescence" (p. 77). Parenting practices (monitoring, punishing, and structuring of peer affiliations) continue to influence children's behavior during their adolescent years. Mothers who are ill may find it difficult to provide effective parenting. Disciplinary styles may need to be altered to accommodate the ill mother's changing abilities; her participation in her child's activities also may be compromised (Catanzaro, 1990; van Mens-Verhulst, Radtke, & Spence, 2004).

Breastfeeding, which is considered a symbol of nurturing mothers, also can be difficult for women with FM. Schaefer (2004) conducted research on a small group of mothers with FM who breastfed their infants. Due to the stiff and sore muscles and "unremitting fatigue" of FM, they were not successful in their breastfeeding attempts and this failure created a feeling of depression and sadness for them.

In their research report on parents with arthritis, Foster, Wade, Harrison, and Barlow (1998) found that the role of being parents increased the difficulties already experienced by people with arthritis (i.e., loss of function and roles). Parents with arthritis especially were concerned with “the change in roles of parents and children, such as small children carrying out activities normally reserved for much older children; expectations of parenthood; inability to do things as ‘normal’; and associated feelings of guilt” (Foster et al., 1998, p. 438). They also found that many parents were reluctant to ask for help in their parenting duties. In another study on parenting with arthritis (Barlow et al., 1999), participants reported that fatigue, pain, and restricted physical functioning interfered with their ability to parent that resulted in feelings of guilt, frustration, anger, and depression. Katz (2006) found low birth rates among women who had RA. Those who were diagnosed at an early age (age 18 years or younger) had the fewest pregnancies. Approximately 20% reported that having RA was a factor they considered when making childbearing decisions.

Effects of Mothers' Illness on Children

Children's adjustment to parental illness is dependent on many factors which include: (1) the type and severity of the parent's disease, (2) whether the disease is acute or chronic in nature, (3) gender of the ill parent and child, (4) age of the child, (5) time of the onset of the parent's illness (prior to child's birth, during childhood, during adolescence), (6) degree of physical impairment of the patient, (7) whether the illness is heritable or nonheritable, (8) degree of the patient's cognitive impairment and emotional distress related to the illness, and (9) characteristics of treatment (e.g., lengthy hospitalizations, presence of severe side effects). (Worsham et al., 1997, p. 197)

Overall, a parent's medical illness seems to have an adverse impact on children's psychological adjustment, mainly through internalizing problems or negative affect. Age

or developmental level of the child seems to be an important factor; adolescents report more adjustment difficulties than younger children. However, children of physically ill parents still tend to fare better than those with psychologically ill parents (Worsham et al., 1997).

According to Howes, Hoke, Winterbottom, and Delafield (1994), studies suggest that parental illness can impact children's psychosocial adjustment. "...[T]he greater the parent's physical impairment, the greater the risk for adjustment problems in the children" (p. 3). Also, greater illness and more intensive medical treatments lead to poorer child functioning. If temporary separations between mother and children are necessary, anger at being abandoned and fear of losing their mother are typical reactions (Brenner, 1984). Ryan (1999) reported that most children of RA parents appear to adjust well. Those children with difficulties had parents who were not able to accept their medical condition and/or the children "resented their parent's illness, and showed little consideration or compassion" (Ryan, 1999, p. 511).

Segal (1998) found that the illness of one parent can seriously undermine the children's trust of both parents. "Consciously or unconsciously, the child may blame the 'healthy' parent for the illness or may fear they will turn against the child" (Segal, 1998, p. 502). These feelings may force children to take on the role of the ill parent because they believe that they are now alone or that they are the only caregiver for the ill parent. Children with ill parents may develop aggressive and guilty feelings toward both parents and/or other caregivers.

Often chronically ill mothers mention that they are not capable of meeting the needs of their children and they feel as though they neglect them. Child neglect can be defined as children whose caretakers "are unwilling or unable to become involved with them and who are emotionally and sometimes physically absent" (Brenner, 1984, p. 115). Three forms of

child neglect are: physical, educational, and emotional. Physical neglect occurs when living conditions are unhealthy (unsanitary) with lack of sufficient food in the dwelling. Often children are unbathed and dirty. Educational neglect occurs if children are not registered for school or if they are kept at home for three or more days per month to earn money or care for siblings (Brenner, 1984). Emotional neglect occurs when parents ignore or are passively indifferent to their children's requests for attention and affection. There are varying degrees of each form of neglect. However, unintentional parental neglect is a concern for chronically ill mothers.

Early exposure to illness, "either directly or within the family, has been linked to the development of medically unexplained symptoms both in childhood and adult life" (Fisher & Chalder, 2003, p. 439). There may be a transmission of illness behaviors and beliefs from one generation to the next through learned experiences (Crane & Martin, 2004).

Adolescent Adjustment

Adolescence is a stage in life where extensive physical, social, and psychological changes occur. Some adolescents embrace these changes and view this as a time for further growth as they seek to discover their identity and separate from their parents. Others find the changes overwhelming and have difficulties adapting to new demands and expectations (Rice, Herman, & Petersen, 1993).

These reactions are consistent with Power's (1977) study of adolescents with chronically ill parents. He discovered that adolescents displayed either positive or negative reactions to their parent's chronic illness. Negative adolescent reactions included resentment and flight. Increased hypochondriacal symptoms also were reported. Other studies reconfirmed this (Allaire, 1988; Hirsch, Moos, & Reischl, 1985; Morgan et al., 1992). Positive adolescent reactions included utilizing the parent's illness as an opportunity for personal growth, developing a more cohesive parent-child relationship,

increasing sensitivity toward others, and instilling a feeling of accomplishment (Blackford, 1992; Johnston, Martin, Martin, & Gumaer, 1992; Mukherjee et al., 2002). The ability to assume additional family responsibilities and care for ill parents developed a sense of hope in the adolescents. They felt that their efforts were important to the parent and other family members. However, continual feelings of anxiety and mourning of gradual family loss were common to all adolescents (Power, 1977).

Older children are more mature than younger children in their thinking. They can identify with parental illness and better understand the resulting difficulties. Their reactions tend to be closer to those of an adult with feelings of apprehension, loneliness, helplessness, anger, and “disappointment about the future for self and the family” (Johnston et al., 1992, p. 227). They may feel anger toward the ill parent and then guilt because of this. Embarrassment and shame about the illness is a common reaction. Personal feelings may be internalized because they feel a need to act grownup.

Morgan et al. (1992) studied the impact of physically ill parents on adolescents. These adolescents exhibited greater somatization and hyperactivity than peers with non-ill parents (Mikail & Baeyer, 1990). Furthermore, longitudinal data from the National Survey of Health and Development (Resnick et al., 1997) has indicated that adolescents with physically ill parents attend school less regularly, score lower on academic tests, and drop out of school sooner. The authors listed potential factors that could provide protection to these children such as clearly defined roles, a return to the best possible physical functioning of the affected parent, ample financial resources, a good premorbid marital relationship and effective coping mechanisms. Drotar (1994) suggested that adaptive temperament, socializability, and IQ (which have been shown to be protective factors against stress for children) also may provide a positive impact when dealing with the stress of parental health problems.

Effects of Maternal Depression

Depression is common in chronically ill mothers. It can greatly interfere in their ability to perform their daily functions which may lead to interpersonal, financial, and occupational difficulties (Gordon et al., 1989). Maternal depression has been linked to impaired parenting because mothers may become unresponsive, hostile, critical, intrusive, withdrawn, or inattentive to their children (Bigatti & Cronan, 2001; Blackford, 1992; Brennan, Brocque, & Hammen, 2003; Burge & Hammen, 1991; Burt et al., 2005; Hamilton et al., 1993; Pascoe, Stolfi, & Ormond, 2006; Whiffen, Kerr, & Kallos-Lilly, 2005; Zahlis & Lewis, 1998). Maternal depressive symptomatology “also may increase the probability that parental tension will spill over into negative interactions with children” (Almeida et al., 1999, p. 50).

Parental depression has been shown to be related to child adjustment and development (Henderson, Sayger, & Horne, 2003; Thomas, Forehand, & Neighbors, 1995). Woods and Lewis’ (1995) study on women with chronic illness found that depressed behavior of mothers affected their children’s development, particularly in areas of peer interaction and self-esteem. Maternal depression also has been correlated with depression in children (Burke, 2003; Hammen et al., 1987; Hammen & Brennan, 2003; Robila & Krishnakumar, 2006). Children’s cognitive, emotional, and behavioral problems such as aggression, lower intellectual competence, hyperactivity, antisocial behavior, and social inhibition have been associated with parental and maternal depression (Conrad & Hammen, 1989; Kim-Cohen, Moffitt, Taylor, Pawlby, & Caspi, 2005; Leftwich & Collins, 1994; Nelson, Hammen, Brennan, & Ullman, 2003; Spence, Najman, Bor, O’Callaghan, & Williams, 2002). Parental depression also has been associated with increased risks in their children for depression, substance abuse, somatic symptomatology, internalizing problems, school problems, and behavioral impairment (Brody et al., 1999; Conrad & Hammen, 1989;

Frankel & Harmon, 1996; Hamilton et al., 1993; Hirsch et al., 1985; Jacob & Johnson, 1997; Keller et al., 1986; Murray, Halligan, Adams, Patterson, & Goodyear, 2006; Steele, Forehand, et al., 1997).

Jacob and Johnson (1997) described the effect of parental depression on children as a “family systems model of depression” since the parent’s depression impacts relationships within the family. “Parental depression may have broader influences on the family than previously acknowledged” (Jacob & Johnson, 1997, p. 404). When a depressed mother is not accessible to her children, the nature of their relationship is changed. This alteration in the family structure is described as a form of morphogenesis by Woods and Lewis (1995).

Children’s Depression

Prior to adolescence, girls and boys have the same rate of depressive symptoms. However, beginning in adolescence and continuing into adulthood, females have significantly higher rates of depressive symptoms than males (Burt et al., 2005; Lyons, Carlson, Thurm, Grant, & Gipson, 2006). Rice et al. (1993) also reported that during adolescence, the rate for depression abruptly increases with it being much higher for girls than for boys. This may be due to the different challenges that emerge during this time, such as gender stereotypical expectations and role conflicts, but it also may be due to adolescent girls’ higher frequency for disclosing affective responses than boys (Hankin, Mermelstein, & Roesch, 2007). In addition, “[c]hildren of depressed parents are at greater risk for developing depression, both from their increased genetic vulnerability and from the lack of availability and stability of their ill parent” (Hendren, 1990, p. 259).

Symptoms of adolescent depression can vary. Typically, they include indecisiveness, social withdrawal, low self-esteem, pessimism, fatigue, loss of interest or pleasure in activities, persistent sadness, inability to sleep, and decreased appetite (Bernt & Zinn, 1988). However, atypical symptoms may include increased appetite and sleeping, weight

gain, not feeling better in response to pleasurable activities, slow reactions and movement, and difficulty engaging in conversation (Powell, Denton, & Mattsson, 1995; “Depression in Children and Adolescents”, 2000). A 10-year follow-up study of children with depressed parents revealed a higher incidence of depression, panic disorder, phobias, and alcohol dependence than for those with non-depressed parents. As adults, these children had lower levels of functioning in their work, home, marriage, and their own families (Beardslee, Versage, & Gladstone, 1998).

Effects of Parental Chronic Pain on Children

Research regarding the influence of parental chronic pain on children has provided mixed results. Some studies have found an association between parental and child pain (Evans & Keenan, 2007). Saunders, VonKoroff, LeResche, & Mancl (2007) found that specific pain conditions, such as back, head or stomach pain, co-occurred in mothers and their children. Mikail and Baeyer (1990) stated that “as many as 78% of individuals with chronic pain come from families in which at least one family member has chronic pain” (p. 51). The results of their study on the relationship between parental chronic pain and children’s general adjustment showed that children of chronic headache sufferers had more somatic concerns than children of headache-free parents. Jamison and Walker (1992) found that parents with higher levels of emotional distress, pain behavior, and disability had children who reported more frequent episodes of pain. They concluded that “children of parents with chronic pain may be at risk for illness behavior, especially when the parents exhibit reactions to their pain” (p. 329).

However, other studies have found no association between parental and child pain. In their study on the impact of parental chronic pain on children, Roy, Thomas, Mogilevsky, and Cook (1994) concluded that there was little evidence of parental chronic pain affecting the psychosocial well-being of their children. Similarly, Jones, Silman, and Macfarlane

(2004) concluded that “[p]arental pain is not a risk for child pain. Pain behaviour is not learned. Rather, child pain is probably attributable to individual factors and the social environment” (p. 1152). More research is needed to resolve this conflicting evidence.

Rheumatoid Arthritis

Incidence, Definition, and Symptoms

According to data from the National Health Interview Survey for 2003-2005, an estimated 21.6% (46.4 million or approximately 1 in 5) U.S. adults have doctor-diagnosed arthritis (CDC, 2007; Hootman, Bolen, Helmick, & Langmaid, 2006). Arthritis is the leading cause of disability in our country. Although it is associated with substantial activity limitation, reduced quality of life, high health-care costs, and work disability, nearly two-thirds of affected people are less than 65 years-old. Arthritis-attributable work limitation “is highly prevalent, affecting millions of Americans and one-third of adults with doctor-diagnosed arthritis” (Theis, Murphy, Hootman, Helmick, & Yelin, 2007). During 2003-2005, nearly 19 million people reported arthritis-attributable activity limitations, and in 2003, direct medical costs for this disease were \$81 billion (CDC, 2007; Hootman et al., 2006). RA occurs in approximately 1% of the U.S. population or 2.1 million people. “[S]ome recent studies have suggested that the overall number of new cases of rheumatoid arthritis actually may be going down” (National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), 2004a, n.p.). Seventy percent of those affected by RA (1.5 million) are women (Arthritis Foundation, 2007c; MFMER, 2006; NIAMS, 2004a). Work disability is a serious problem in RA (Eberhardt et al., 2007; Verstappen et al., 2007). RA is estimated to economically cost the United States approximately \$65 billion per year in lost productivity and medical care (CDC, 2003; Orenge, Wei, Molinari, Hale, & Kunik, 2001). “The cost of medical care for RA patients is reported to be three times higher than that for persons of the same age and gender who do

not have RA” (Orengo et al., 2001, p. 46).

The term “arthritis” encompasses over 100 different diseases and conditions whose primary characteristics include aches, pain, swelling, and stiffness in or around joints (CDC, 2007; Sacks & Sniezek, 2003). Rheumatoid arthritis (RA) is one of the four most common forms of arthritis (CDC, 2007). (Osteoarthritis, fibromyalgia, and gout are the other three conditions.)

RA meets the requirements of a chronic illness since it is a long-term illness (sometimes with permanent disability), is treatable but not curable, and interferes with the person's normal physical, psychological, and/or social functioning. It also is characterized by relatively stable periods of time that are interrupted by periods of acute episodes of illness which may require medical attention. RA is a chronic, systemic, inflammatory disease that leads to restricted joint mobility and pain upon movement (Hagen, Smedstad, Uhlig, & Kvien, 1999; Holm, Rogers, & Kwoh, 1998; Moran, 1996). Beyond the typical symptoms of arthritis (pain, stiffness, swelling, and loss of joint function), RA has several unique features that differentiate it from other types of rheumatic diseases or conditions (MFMER, 2006; NIAMS, 2004a): These include:

1. Tender, swollen, warm joints with redness. RA is an autoimmune disease; the immune system attacks the person's own cells within the joints. In response, the body's defense system sends white blood cells (a normal part of one's immune system) to the joint lining or synovium. This causes a reaction or inflammation known as synovitis and it results in red, warm, swollen, puffy, painful joints that are typical symptoms of RA.

2. Symmetrical patterns of inflammation. Usually, RA occurs in both sides of the body at the same time. For example, if the right knee is affected, then the left knee will be as well.

3. Wrist and finger joints closest to the hand often affected. Although RA can affect

many of the joints in the body, it frequently occurs in wrists, hands, feet, and ankles.

4. Fatigue, occasional fever, malaise (general feeling of weakness or not being well).

5. Pain or stiffness in the joints or muscles especially in the morning or after periods of inactivity that last longer than 30 minutes. Inflammation and pain create loss of strength resulting in atrophied muscles (Shaul, 1995).

6. Symptoms in other body parts besides the joints. Some people with RA may develop rheumatoid nodules - bumps under the skin near the inflamed joint(s), anemia, dry eyes and mouth from inflamed tear and salivary glands, neck pain, and/or inflammation of the lining of the lungs, blood vessels, or the sac enclosing the heart (pericardium).

Pain is the most frequently reported symptom of RA (Edwards, Bingham, Bathon, & Haythornthwaite, 2006). In a 2003 nationwide survey among adults, 19% reported that they had experienced arthritis/joint pain within the past year (Research America, 2003). Often RA is accompanied by fatigue (Mancuso, Pincon, Sayles, & Paget, 2006). These two symptoms of RA are strongly associated with people's quality of life and they can affect participation in psychological intervention, medical treatment, and physical therapy (American Chronic Pain Association, n.d.; Stone, Broderick, Porter, & Kaell, 1997).

According to Mengshoel and Forre (1993), there are two components to pain: (1) sensory - related to somatic sensations, and (2) affective - related to people's reactions against pain.

Together these comprise the pain experience.

Pain is reported more frequently by people who suffer from depression, emotional stress, fatigue, and anxiety (Croft, Rigby, Boswell, Schollum, & Silman, 1993; Snelling, 1990; Ward, 1994; Zautra, Parrish et al., 2007). According to Minnock, FitzGerald, and Bresniham (2003), women perceived pain as the predominant impairment of their health status. However, even with high pain levels, the quality of women's social roles as wife, mother, employee, friend, and homemaker influences their psychological well-being.

Those with high pain level and high role quality experience more purpose in life and less depression than women with high levels of pain and low role quality (Plach, Heidrich, & Waite, 2003; Plach, Napholz, & Kelber, 2005). Self-efficacy (“the belief that one has the capability to manage the demands of a challenging situation in such a way as to attain a desired outcome”) also has been attributed to lower levels of pain and negative mood, and higher levels of positive mood (Lefebvre et al., 1999, p. 425). Successful pain coping strategies may be attributed to greater self-efficacy (Keefe, Kashikar-Zuck et al., 1997).

“Up to 98 percent of people with rheumatoid arthritis (RA) report fatigue... . The percentage grows higher when depression or conditions like fibromyalgia,... are present, too” (Arthritis Foundation, 2007c, p. 1). One in five to one in seven people with RA also have FM (Leeb, Anedl, Sautner, Nothnagl, & Rintelen, 2004; Naranjo et al., 2002; Richards & Siegfried, 2006). This fatigue can be long-lasting and unwarranted because there has been no excess activity and the joints may be feeling fine (Arthritis Foundation, 2007c). To reduce fatigue, Carty, Conine, Holbrook, and Riddell (1993) recommended that women pace themselves to provide both systemic and joint rest, wear braces to support their joints, have two rest periods per day, sleep 8-10 hours per night, and sit when possible during the day. Periods of exercise also should be incorporated in this regimen.

Joint stiffness is another highly reported symptom of RA. Its nature and cause remain unclear. A study by Haigh, McCabe, Halligan, and Blake (2003) provided evidence that stiffness is not caused exclusively by destructive physical changes in joints. Three patients who experienced perceived joint stiffness (PJS) still reported stiffness in a limb even after it was amputated. The authors hypothesized that changes in the central nervous system also may contribute to joint stiffness.

In general, women with chronic illness report more physical symptoms and poorer physical health, seek health care later, and have greater functional limitations than men

(O'Neill & Morrow, 2001). Differences between genders in reporting symptoms, including those of RA, may be due to socio-cultural values whereby it is more acceptable for women to be ill and discuss it. Women report more severe RA symptoms than men. This may be due to their experiencing more severe disease, having greater symptom perception, feeling less societal pressure to be "brave", or hormonal factors. "The issue of symptom reporting is important in RA because physicians rely heavily upon symptom reports to make treatment decisions" (Katz & Criswell, 1996, p. 441).

Diagnosis and Treatment of RA

RA may be difficult to diagnose in its early stage because symptoms vary from person to person and they can mimic other conditions. Since there is no single test for this disease, physicians diagnose RA based on a variety of tools such as self-report of symptoms, physical exam, medical history, x-rays, and lab tests including an erythrocyte sedimentation rate (ESR) and rheumatoid factor antibody (Arthritis Foundation, 2007c; MFMER, 2006). People are diagnosed with RA when they meet at least four of the following seven criteria established by the American College of Rheumatology (ACR): (1) morning stiffness in and around joints lasting at least one hour before improvement, (2) arthritis in three or more joint areas with soft tissue swelling, (3) arthritis of hand with at least one swollen area, (4) symmetric swelling of same joint areas on both sides of the body, (5) rheumatoid nodules subcutaneous, over bony areas, (6) presence of serum rheumatoid factor in blood test, and (7) radiographic changes (erosion or bony decalcification) in hand or wrist joints. The first four criteria must have been present for at least six weeks (Arnett et al., 1988).

Early diagnosis of RA is essential so that treatment can be initiated as soon as possible in the course of the disease to prevent or limit the destruction of joints (Barrett, Scott, Wiles, & Symmons, 2000; Eberhardt, Larsson, & Nived, 1993; Moorehead & Fye, 2005;

NIAMS, 2004a; Wise & Isaacs, 2005). “Researchers studying rheumatoid arthritis now believe that it begins to damage bones during the first year or two that a person has the disease, one reason why early diagnosis and treatment are so important” (NIAMS, 2004a, n.p.). In many cases, the use of disease-modifying antirheumatic drugs (DMARDs) can slow or control the progression of this condition (Machold et al., 2002; MFMER, 2006). Typical goals of treatment for the physician and patient are to relieve pain, reduce inflammation and fatigue, slow or eliminate joint erosion, improve one’s sense of well-being, gain control over the unpredictability of the disease, and increase mobility and the ability to function (Carr et al., 2003; Ryan, Hassell, Dawes, & Kendall, 2003). This is done through a variety of approaches such as medications, surgery, and lifestyle changes (i.e., physical therapy, rest and exercise, weight control, healthy diet, stress reduction) (Choi, 2004; MFMER, 2006; National Library of Medicine, 2005). However, some of these treatments produce unwanted side effects that reduce the quality of life and the physical and mental functioning of people.

Disease Activity Pattern for RA

The activity level of this disease fluctuates and is uncertain. Unpredictable periods of remission often are followed by acute, painful exacerbation. These flare ups (flares) and relapsing episodes can occur without warning and if they are prolonged, there often is loss of function, significant work disability, and disfigurement (Barlow, 1998; Barlow, Turner, & Wright, 1998; Kennedy & Stokes, 2002; Potter & Zautra, 1997; Smith & Wallston, 1992). During periods of remission, the pain, swelling, difficulty in sleeping, and weakness decrease or disappear.

Shaul (1997) stated that rheumatoid arthritis is “prototypical of many chronic illnesses because it has a profound impact on activities of daily living. It frequently occurs during a person’s most productive years and continues throughout life” (Shaul, 1997, p. 199).

Structural damage and functional loss appear to be greatest in the first five years of the disease (Kroot et al., 2000; Meenan, Kazis, Anthony, & Wallin, 1991). Yet, there is a progressive course to this disease (Moran, 1996; Zautra & Manne, 1992).

It has been thought that stressful life events, including negative childhood events, may play a part in the development of RA. However, current research does not support this (Arango & Cano, 1998; Carette et al., 2000; Dougall & Baum, 2001; Potter & Zautra, 1997). Instead, it appears that increases in daily stressors (e.g., demands of RA care, pain, fatigue, functional impairment) and interpersonal stress are associated with increased RA symptoms and disease activity (Affleck, Urrows, Tennen, & Higgins, 1997; Katz, 1998; NIAMS, 2004a; Zautra et al., 1998; Zautra et al., 1997). Women with strong marital relationships were less likely to be vulnerable to interpersonal stress (Zautra et al., 1998).

Prognosis and Progression of RA

In terms of joint destruction, the progression of the disease occurs at a median rate of about 2% to 3% per year (Jantti, Kaarela, Belt, & Kautiainen, 2002). Between 50% to 70% of people with RA remain capable of full-time employment, but little is known about how job stress affects them (National Library of Medicine, 2005; Reisine & Fifield, 1995). However, after 10 or more years of RA, those people with severe RA may experience occupational disability and be unable to perform even simple activities of daily living such as dressing, eating, toileting, washing or household chores (Katz, 1995; Moran, 1996; National Library of Medicine, 2005; Wright et al., 1996). “[W]ithin approximately 10 years of disease duration, 50% of patients with RA who had been working during the year of diagnosis become no longer employed, mostly because of the RA” (Vliet Vlieland et al., 1994, p. 803). When a person with RA also has FM, there is even a worse prognosis for functional ability (Naranjo et al., 2002).

The progression of RA can be divided into three stages. During the first stage, white

blood cells travel to the synovial lining of the joint where redness, stiffness, warmth, and pain occur. In the second stage, abnormal growth of the synovial cells causes the membrane to become thicker which makes the joint swollen and puffy. In the third stage of RA, the inflamed synovial cells release enzymes that invade and destroy cartilage and bone within the joint. The joint then loses its shape (deformed) and alignment, becomes weak and incapable of working normally, and pain increases (Abbott Laboratories, 2007; Arthritis Foundation, 2007c; MFMER, 2006; NIAMS, 2004a).

The disease course of rheumatoid arthritis varies considerably from person to person. Early in the disease, people may notice general fatigue, occasional fevers, soreness, stiffness and aching (National Library of Medicine, 2005; NIAMS, 2004a). For some people, this may last only a few months to a year or two and then disappear, leaving no apparent damage (NIAMS, 2004a). Remission is most likely to occur during the first year with the probability decreasing as time progresses (Moran, 1996; National Library of Medicine, 2005). Other people may experience a mild or moderate disease course with alternating periods of worsening and remission of symptoms. For other people (approximately 30% of those with RA), this disease will be progressive and severe with nearly continual symptoms that last many years and lead to serious disability, joint damage, and deformity (King, 2003; NIAMS, 2004a). However, even with this severe form of RA, people can retain flexibility in many joints. Young (1992) explained that:

[a]lthough 10 to 20% of patients have a monocyclic disease course of mild symptoms, with remission occurring within 2 years, and an additional 10 to 15% experience a progressive, disabling disease course in spite of appropriate therapy, most RA patients (approximately 70%) experience unpredictable exacerbations and remissions of disease activity with progressive deformity and disability. (p. 619)

A topic that is not often mentioned with RA is the reduction in life span of people with

this disease. People with RA have a shortened life expectancy by 3 to 7 years compared with the general population of the same age and sex. “Those with severe forms of RA may die 10-15 years earlier than expected. However, as treatment for rheumatoid arthritis improves, severe disability and life-threatening complications appear to be decreasing” (National Library of Medicine, 2005, p. 4).

Since RA is a systemic, chronic disease that creates inflammation throughout the body, the relationship between RA and cardiovascular disease recently has gained attention (Book, Saxne, & Jacobsson, 2005; Dedhia & DiBartolomeo, 2002; Janssen, Karnad, & Guntupalli, 2002; Klocke, Cockcroft, Taylor, Hall, & Blake, 2003; Soloman et al., 2003; Watson, Rhodes, & Guess, 2003; Wolfe, Freundlich, & Straus, 2003). An increased risk for cardiovascular disease has been associated with RA (Dessein & Joffee, 2006; Farragher & Bruce, 2006; Wolfe et al., 2003). However, at this time, the reasons for this are not completely understood although many believe that it is related to the systemic inflammatory burden of RA (Farragher & Bruce, 2006; Watson et al., 2003).

Besides the greater incidence of cardiovascular mortality in RA patients, “mortality from lung disease in patients with RA is about twice that of the general population” (Dedhia & DiBartolomeo, 2002, p. 844). In addition, there is evidence of early bone loss in premenopausal women who have RA (Tourinho, Stein, Castro, & Brenol, 2005) and of RA being triggered by *Proteus mirabilis* microbes that cause urinary tract infections (Ebringer & Rashid, 2006). Chronic systemic inflammation also seems to predispose people to both insulin resistance and diabetes mellitus (Doran, 2007).

Risk Factors for RA

While a specific cause of RA is unknown, it is suspected that there are several interacting factors involved in developing this disease. These may include:

Genetic Predisposition

Researchers have determined that when one identical twin has RA, the other sibling has a 15% chance of developing the disease. This is substantially higher than the 0.08% risk in the general population. Also, certain genes (HLA-DR4) connected with the immune system have been associated with the tendency to develop RA. Yet some people with RA have these genes and others do not. Researchers still are trying to find specific genes that are responsible for the susceptibility, persistence, and severity of RA and believe that more than one gene is involved (Arthritis Foundation, 2007c; NIAMS, 2004a; Reveille, 2005; Symmons, 2002).

Immune Response

RA is known as an autoimmune disease because the immune system attacks its' own body tissues. Researchers do not know what triggers this type of response, but chronic joint inflammation causes a release of proteins that, over time, can create thickening of the synovium (joint lining). This leads to joint destruction and damaged cartilage, tendons, ligaments, and bones (MFMER, 2006). Potter and Zautra (1997) reported that stressful life events can affect the disease activity of RA. "Major life events such as family death, divorce, and catastrophic illness... [can] suppress some immune parameters" and produce a large decrease in disease activity (Potter & Zautra, 1997, pp. 319, 322). Small life events, defined as "frequent, minor, short-lasting daily stressful conditions such as family arguments, financial concerns, and general hassles associated with daily life...[can] enhance other important immune responses" (Potter & Zautra, 1997, pp. 319, 322). These can cause an increase in RA symptoms.

Infection

Some researchers believe that RA is triggered by viral or bacterial infections. While there is no single organism that is responsible for all cases of RA, a substantial number of

people do develop this disease within a few weeks of an infection. This may be more likely in people with an inherited predisposition for RA (Arthritis Foundation, 2007c; MFMER, 2006). However, RA is not a contagious disease (NIAMS, 2004a).

“Immunizations can also act as a trigger for RA in some people” (Symmons, 2002, p. 715).

Age and Ethnicity

Although RA can occur at any age and there is not a firm agreement about the age of peak onset, typical ages of onset range between 20 and 55 years (King, 2003; MFMER, 2006; NIAMS, 2004a; Smith & Zautra, 2002). Although children and young adults can develop RA (known as juvenile rheumatoid arthritis), most cases occur during the child-rearing years. Prevalence increases until by age 65, 5% to 7% of the population may have RA (Walsh, Blanchard, Kremer, & Blanchard, 1999). It occurs in all races and ethnic groups ranging from 0.5% to more than 5% (King, 2003; NIAMS, 2004a). Native American people have the highest frequency of this disease ((NIAMS, 2004a; Padilla & Perez, 1995; Symmons, 2002). A recent study by Yazici, Kautiainen, and Sokka (2007) indicated that of the Hispanic, Caucasian, and African-American patients with early RA, Hispanic patients “scored worst in all self-report measures . . . , with statistically significant differences in MHAQ [Multidimensional Health Assessment Questionnaire] functional score, psychological distress, and morning stiffness” (p. 311).

Personal Lifestyle

Several researchers also have noted a relationship between lower formal education level and higher prevalence and severity of RA (Brekke et al., 2003; Eberhardt & Fex, 1995; Pedersen, Jacobsen, Klarlund, & Frisch, 2006; Pincus & Callahan, 1993; Verbrugge, Gates, & Ike, 1991; Vliet Vlieland et al., 1994; Young, 1992). A hypothesis offered by Pincus and Callahan (1993) proposes that lower formal education level is a “composite/surrogate variable that identifies behavioral risk factors” associated with a

predisposition to developing most chronic illnesses and having a poorer prognosis for chronic diseases (p. 144). These risk behaviors may include “diet, smoking, compliance, efficiency in using medical services, problem-solving capacity, sense of personal responsibility, capacity to cope with stress, life stress, social isolation, health locus of control, and learned helplessness” (Pincus & Callahan, 1993, p. 144). Additional research is needed before the mechanisms by which lower levels of education increase the risk of RA can be fully understood.

Symmons (2002) noted that for more than 25 years, smoking has been associated with production of the rheumatoid factor in men. While recent studies show that cigarette smoking increases the risk of RA, Krishnan, Sokka, and Hannonen (2003) found that a past history of smoking increased the risk of rheumatoid arthritis in men but not women. In contrast, alcohol consumption may provide modest protection against this disease. Many studies have been conducted to associate specific foods (olive oil, tea, fish oil, coffee, meat) with the onset of RA (Oliver & Silman, 2006). Additionally, poorer living conditions and stress are associated with a higher incidence and poorer prognosis of RA (Padilla & Perez, 1995; Rupp, Boshuizen, Roorda, Dinant, Jacobi, & van den Bos, 2006). However, the research findings have been contradictory and further studies are required.

Hormonal Factors

Since RA is more common in women throughout the world, hormonal factors are assumed to play a part in the development of this disease (Oliver & Silman, 2006). Sixty percent of all arthritis cases occur in women ages 15 and older (CDC, 1999). RA affects women three times more often than men and is rare before menarche (Dwyer, 1997; Hannan, 1996; King, 2003; Symmons, 2002). The incidence of RA is nearly half in women who have taken oral contraceptive pills (Symmons, 2002). It is rare for RA to begin during pregnancy; the onset of this disease is reduced by 70% during this period and

its activity frequently subsides during pregnancy (Oliver & Silman, 2006). However, there is a much higher incidence of developing RA or experiencing a flare in the weeks following delivery (Fiddler, 1997; Hannan, 1996; Symmons, 2002). Some researchers believe that deficiencies or changes in certain hormones may trigger RA, especially in a genetically susceptible person who has been exposed to a triggering agent in the environment (NIAMS, 2004a). To date, there is no evidence hormone replacement therapy affects the development of RA.

Personality

Approximately two decades ago, the propensity to develop RA was attributed, in part, to people who had an “arthritis personality” and exhibited anxiety, anger/hostility, and depression. The idea that a person’s overall personality causes the development of RA has since been abandoned due to lack of supporting research (Friedman & Booth-Kewley, 1987; Young, 1992). However, as indicated earlier, various affective and cognitive behaviors have been found to affect the severity of symptoms in chronic illness and the person’s functioning.

Influence of Psychosocial Factors

Social Support

RA has been described as a disease that affects both social and physical health. Decreased pain and increased mobility in RA have been associated with social support (Evers et al., 1998; Keefe, Affleck et al., 1997). RA not only leads to physical disability, but it also can affect social roles and interactions (Bediako & Friend, 2004; Walker, 2007). Bolwijn, Van Santen-Hoeufft, Baars, and Van der Linden (1994) found that the size of social networks for RA patients did not differ from the general population, but networks did differ in composition because they contained fewer intimate friends and family members. Most social networks seemed to “consist of neighbors and partners from the

spouse's colleagues; people who are not part of the network because of the patient's own choice, but merely as a coincidence" (Bolwijn et al., 1994, p. 49). It appeared as though people afflicted with RA were unable to or did not want to take the initiative to meet new people. This left them dependent on only a few people in their social network to meet their psychosocial needs.

When people are newly diagnosed with RA, one of their first concerns is employment. People with RA face an earlier retirement and/or decreased annual income due to the impact of this disease (Barrett et al., 2000; Eberhardt et al., 1993; Reisine & Fifield, 1995; Yelin & Callahan, 1995). The workplace has been identified as a "critical locus for social support" (McQuade, 2002, p. 212). In her study of job performance of hypothetical workers with varying health problems, McQuade (2002) found that workers with RA were perceived more negatively than paraplegic or healthy workers. RA workers were deemed to have poorer overall job performance and interpersonal job skills. This suggests that people with RA may leave work not only because of the changes in their health, but also because of the lack of social support in the workplace.

Relationship to Divorce

It is widely assumed that there is a higher rate of divorce in couples where RA is present. However, conflicting findings on the relationship between RA and the rate of divorce have been observed by this researcher. Several studies have reported an association of RA with a higher rate of divorce (Katz & Yelin, 1994; Medsger & Robinson, 1972; Reisine, 1995). McDuffie's (1985) research found that the rate of divorce for the RA patients in his study was 70% higher than that for the general population. Medsger & Robinson (1972), in their comparative study of divorce status in RA and other rheumatic conditions, reported that a higher prevalence of divorce in RA couples was due to a lower rate of remarriage; women with RA who divorced were less likely to remarry.

In the marriages that ended in divorce, “[e]ducational achievement discrepancy between marital partners” was a significant factor (Medsger & Robinson, 1972, p. 274).

Hellgren (1969) reported that when participants were matched for age, sex, occupation and geographical areas in Sweden, the research findings did not support a significant association between RA and divorce. Additionally, in a study examining the marital status of more than 7,000 rheumatic disease patients, Hawley, Wolfe, Cathey, and Roberts (1991) concluded that divorce was not more common in RA patients. However, remarriage after divorce was “2 to 5 times less common in patients with RA than in controls. These observations suggest... that the illness *per se* does not play an important role in marital break up, but that once divorce occurs, RA is a major factor in preventing marriage” (Hawley et al., 1991, p. 660).

Progress in RA Research

During the past few years, several medical advances have occurred in the area of RA, one of which is the rapid advancement of genetic decoding. Since approximately “60% of the variation in population occurrence of [RA] has been attributed to genes”, it is hoped that genetic coding will transform clinical management of this disease (MacGregor & Steer, 2006, p. 2377). Biological response modifiers or biologic medications are new drugs that are more directed, defined and targeted than the DMARDs. They have a more targeted and rapid onset of action that powerfully reduces inflammation and stops progressive structural damage (Fleischmann, 2005; Shiel, 2007b; NIAMS, 2004a). Recently, researchers have theorized that because the effects of RA vary greatly from individual to individual, this condition may actually be several different diseases that share common characteristics or features (Arthritis Foundation, 2007c). This will be a new direction of research in RA.

Fibromyalgia

Definition, Incidence, and Symptoms

European literature dating back to the late 16th century has described musculoskeletal aches and pains similar to the illness known today as fibromyalgia (FM) (Inanici & Yunus, 2004; Kurtze, Gundersen, & Svebak, 1999). The term fibromyalgia comes from the Latin word *fibro* meaning fibrous tissue and the Greek words *myo* for muscle and *algia* for pain (NIAMS, 2004b; Powers, 1993). In the past, fibromyalgia has been known by other terms such as fibrositis, fibromyositis, lumbago, muscular rheumatism, chronic muscle pain syndrome, tension myalgias, myofascial pain syndrome, and psychogenic rheumatism (Harth & Nielson, 2007; Reynolds, 1983; Smythe, 1986; Wolfe, 1988). FM is a common condition of widespread body pain in muscles, tendons, and ligaments with multiple tender points. “Tender points are specific sites or pressure points on the body - neck, shoulders, back, hips, and upper and lower extremities - where people with fibromyalgia feel pain in response to slight pressure” (NIAMS, 2004b, n. p.). Although FM is considered to be an arthritis condition, it is not a true form of arthritis (disease of the joints) because it does not cause damage or inflammation of joints, muscles, or other tissues.

Between 3 and 6 million (or as many as one in 50) Americans are affected by FM. “This translates to approximately 2% of the general population, 2% of all patients seen in general practice settings, and 10%-25% of patients seen in rheumatology settings” (Leake, 2001, p. 41). Ninety percent of those affected by FM are women (Leake, 2001; National Library of Medicine, 2006; NIAMS, 2004b; Shiel, 2007a; Weir et al., 2006). They range in age from 20 to 55 years with the peak age occurring during the childbearing years (Leake, 2001; National Library of Medicine, 2006; NIAMS, 2004b; Shiel, 2007a; Weir et al., 2006). However, men and children also can be affected by this illness. “[Twenty-eight percent] of children with mothers who have fibromyalgia also develop it, with close-knit

families reporting more severe cases” (Leake, 2001, p. 41). All races are affected (National Fibromyalgia Association [NFA], 2007a). Gansky and Plesh’s 2007 study involved African-American and Caucasian women with FM and the findings suggested that racial differences exist. “C [Caucasian] women had significantly increased tenderness while AA [African-American] women had more widespread pain” and depression and pain were stronger in African-American women (p. 810). These differences emerged relatively early in life.

FM is associated with significant societal and health care costs. “Women with FM are high consumers of both conventional and CAM [complementary and alternative medicine] services” (Penrod, Bernatsky, Adam, Baron, Dayon, & Dobkin, 2004, p. 1391). Walen, Cronan, and Bignatti (2001) found that higher healthcare costs for women with FM were associated with specific factors such as more comorbid conditions, lower self-perceived health status, worse health status, higher disease severity, less self-efficacy for functioning, higher depression, and less social support. For example, if women with FM also had depression, they were more likely to be higher users of health care services than if they had only FM (Robinson, Birnaum, Morley, Sisitsky, Greenberg, & Wolfe, 2004). A study conducted on health care costs of 33,176 FM patients revealed that “[m]ean (SD) total healthcare costs over 12 months were about three times higher among FMS patients [\$9573 (\$20,135) vs. \$3291 (\$13,643);... median costs were fivefold higher (\$4247 vs. \$822)” (Berger, Dukes, Martin, Edelsberg, & Oster, 2007, p. 1498). In addition, the economic cost of FM was increased greatly when hidden costs of disability and comorbidities were taken into account. It’s estimated that 10% to 40% of FM patients either stop working or change jobs due to FM symptoms (Goldenberg, 1999; Leake, 2001). Robinson, Birnaum, Morley, Sisitsky, Greenberg, and Claxton (2003) reported “[t]he prevalence of disability was twice as high among FM employees For every dollar

spent on FM-specific claims, the employer spent another \$57 to \$143 on additional direct and indirect costs” (p. 1318). Direct costs were calculated from medical and pharmaceutical claims and indirect costs were calculated from disability claims and amount of absenteeism.

FM can severely hamper women’s ability to be productive members of their families and society (Crooks, 2007; Kaplan, Schmidt, & Cronan, 2000; Schoofs et al., 2004). Pain, fatigue, memory and concentration problems, and workplace accommodations affect their ability to remain employed (Bennett, 1996; Crooks, 2007; Lofgren, Ekholm, & Ohman, 2006; Mahalik, Shigaki, Baldwin, & Johnstone, 2006). Although employed women with FM report better physical health and quality of life than those who are not employed, employment has little effect on the mental health aspect of their quality of life (Reisine, Fifield, Walsh, & Dauser, 2004; Reisine, Fifield, Walsh, & Feinn, 2003).

FM is not known as a disease because it does not have an established pathological cause; instead, it is considered to be a syndrome – a group of symptoms occurring together that are characteristic of a specific condition (Arthritis Foundation, 2007a; Wallace, 1997). FM is similar to other arthritic conditions, such as RA, because it causes significant fatigue, pain, and interference with completing daily activities (NIAMS, 2004b). People with FM are 2.14 to 7.05 times more likely to have one or more of the following comorbid conditions: depression, anxiety, headache, RA, chronic fatigue syndrome, irritable bowel syndrome (IBS), and systemic lupus erythematosus (lupus) (Weir et al., 2006). It is estimated that “the majority of those with fibromyalgia also experience chronic fatigue” (Richards & Siegfried, 2006, p. 1). Other common signs and symptoms of FM include: sleep disturbances; facial pain; heightened sensitivity to noise, odors, bright lights and touch; concentration difficulties (sometimes referred to as “fibro fog”); numbness or tingling in hands and feet (paresthesias); mood changes; chest pain; dry eyes, skin, and

mouth; irritable bladder; painful menstrual periods; and dizziness. (Arthritis Foundation, 2007a; Fan, 2004; MFMER, 2007; NIAMS, 2005; Petersen, 2007; Thieme et al., 2004). These symptoms can be triggered or aggravated by stress, cold or humid weather, infectious disorders, non-restorative sleep, physical inactivity, and/or physical/mental trauma and they vary considerably between and within patients (Buesing, 2005).

Pain, fatigue, sleep disturbances and cognitive problems are predominant symptoms of FM. The pain of FM is profound, chronic, and often severe; it varies in intensity, affects all areas of the body, and has symmetrical patterns (NFA, 2007a; Shiel, 2007a). Women with FM often describe their pain with thermal-terms such as hot, on fire, boiling, or burning and as stabbing, shooting, deep aching, throbbing, and twitching (NFA, 2007a; Soderberg & Norberg, 1995).

Complaints of fatigue are shared by both RA and FM individuals with approximately 40% of patients with RA and 76% to 90% of those with FM complaining of significant fatigue (Arthritis Foundation, 2007b; Fan, 2004; Zautra, Fasman, Parish, & Davis, 2007). FM fatigue is described as total exhaustion that interferes with the most minor daily activities and feels as though every drop of energy has drained from the body (NFA, 2007a). It is common to experience exhaustion from even minimal activity. “A review of FM symptoms in 50 patients revealed that 15% were bedridden and could do virtually nothing, 10% were homebound and could not do even light housework and 75% were easily fatigued by normal activity” (Fan, 2004, p. 221).

Sleep disturbances are reported in conjunction with fatigue as well as pain (Onen, Onen, Courpron, & Dubray, 2005). While they frequently accompany rheumatic diseases, more than 75% of FM patients (and 25% to 42% of RA patients) report sleep issues (Drewes, 1999; Theadom, Cropley, & Humphrey, 2007; Wolfe, Michaud, & Li, 2006;). Non-restorative sleep patterns are linked to disease activity, mood, and pain. For FM

patients, sleep disturbances prevent them from getting restful, restorative, deep sleep because their sleep patterns are interrupted continually by “bursts of awake-like brain activity” that limit the amount of time they spend in stage 4 (deep) sleep (NFA, 2007a). A new area of research that is just beginning to be explored is sexual dysfunction in FM women (Aydin, Basar, Keles, Ergun, Orkun, & Batislam, 2006; Shaver, Wilbur, Robinson, Wang, & Buntin, 2006). This may be associated with sleep disturbances or depression – both common symptoms of FM.

More than half of FM patients report mental or cognitive disturbances that result in poor concentration, mood changes, depression, anxiety, forgetfulness, and irritability (NFA, 2007a). Memory loss is 2.5 times greater in FM than in other rheumatic diseases. This symptom is so common to FM that it is sometimes referred to as “fibro fog” (Arthritis Foundation, 2007a; Thieme et al., 2004). According to Dick, Eccleston, and Cromez (2002), many chronic pain patients have attentional functioning deficits and they suggested that this causes impaired cognitive functioning in FM patients. However, Leavitt and Katz (2006), in their study on distraction, found that FM patients’ short-term memory problems occurred when they were exposed to a source of distraction while trying to retain new information.

Diagnosis and Treatment

Fibromyalgia produces widespread pain so severe that it often is incapacitating. Yet, “it is also characterized by the total absence of any definable pathophysiologic or laboratory abnormality, even under the most intense scrutiny” (Fan, 2004). Physicians diagnose FM “by conducting physical examinations, evaluating symptoms, and ruling out other medical conditions” (United States Food and Drug Administration, 2007, n. p.). However, since many diseases frequently occur in combination in FM patients, the diagnosis of another disease still does not rule out the presence of FM (Leake, 2001).

In the 1970s, researchers found that when people with FM were examined physically, there were symmetric points in the muscles, tendons or bony areas that were tender and painful to pressure. Subsequently, many studies have reconfirmed the existence of tender points in FM patients (Fan, 2004). To develop criteria for the classification of FM as an illness, a committee of rheumatologists from the American College of Rheumatology (ACR) conducted a four-year, multicenter study. From this study, the ACR 1990 criteria for the classification of FM emerged. The “criteria for the classification of fibromyalgia are (1) widespread pain *in combination with* (2) tenderness at 11 or more of the 18 specific tender point sites” (Wolfe et al., 1990, p. 160). In addition, the committee abandoned the distinction between primary and secondary FM and adopted the new term fibromyalgia rather than the older term fibrositis.

Unfortunately, not all researchers and physicians agree with these guidelines. Some believe that the criteria for number of tender points is too rigid; people can have FM even if the requisite number of tender points are not found. Other physicians question the validity and reliability of tender points as a diagnostic tool (Fontaine, 2007; Leake, 2001). If physicians are new to diagnosing this illness, they may not palpate the correct area with the appropriate amount of pressure and the examination results will not be valid. Symptoms of FM vary greatly from day-to-day and within the day; patients may not experience their typical pain during the time of diagnosis. “Unfortunately, given the difficulties of diagnosing FM, it is estimated that it takes an average of 5 years from the time the patient first reports symptoms to the time when FM is formally diagnosed” (Fontaine, 2007, p. 1). This does not take into consideration the amount of time that the person may have had the illness prior to reporting it to a physician. Goldenberg (1999) reported that “[m]ost patients with FM have had the symptoms 5 to 7 years before a diagnosis is made” (p. 782).

The major goals of treating people with chronic illnesses are to preserve their quality of life, maintain independence, and minimize functional loss (Strombeck, Ekdahl, Manthorpe, Wikstrom, & Jacobsson, 2000). For people with FM, treatment goals need to include decreasing or eliminating the symptoms (particularly pain and sleep disturbances) and promoting positive health behaviors to improve physical and emotional well-being (Rooks, 2007). Physicians are finding that this requires a multifaceted approach that includes pharmaceutical and non-pharmaceutical strategies. “The wide variety of treatments attests to the complex nature of the disease (Clayton & West, 2006). Often it is necessary to combine treatments to achieve maximum relief from FM symptoms (Burckhardt, 2006; Lemstra & Olsznski, 2005; Pfeiffer et al., 2003; Wallace, Clauw, & Hallegua, 2005; Yousefi & Coffey, 2005).

The following drugs have been used to treat FM symptoms, either alone or in combinations: antidepressants, selective serotonin reuptake inhibitors, muscle relaxers, non-steroid anti-inflammatory drugs, pain medications, anti-anxiety and sleep agents, estrogen replacement therapies, oral corticosteroids, ointments, and tender point injections. Some of these may not be effective in reducing FM symptoms (Lautenschlager, 2000). On June 21, 2007, the U.S. Food and Drug Administration approved the first drug for treating FM. Lyrica (pregabalin) reduces pain and improves sleep for some FM patients (Mann, 2007).

Exercises such as aerobics, strength training, and stretching often are recommended to FM patients (Leake, 2001). Due to widespread chronic pain (particularly in muscles), many FM patients do not feel comfortable exercising. This leads to decreased strength and added fatigue (Richards & Cleare, 2000). Yet, significant improvement in functional capacity can be seen in those who do exercise; however, it is difficult to get FM patients to adhere to this (Da Costa et al., 2005; Dobkin et al., 2006; Dobkin, Sita, & Sewitch, 2006).

In an attempt to improve the quality of life of FM patients, other therapies have been tried such as cognitive-behavioral (learning to think differently about pain), physical, occupational, water, relaxation, stress reduction, magnet, massage, ultrasound, acupuncture, nutritional supplements, chiropractic, yoga, Tai Chi, aromatherapy, breathing techniques, biofeedback, myofascial release, hypnosis, guided imagery, and behavioral weight loss (D'Arcy & McCarberg, 2005; Edinger, Wohlgemuth, Krystal, & Rice, 2005; Fontaine, 2007; Leake, 2001; Menzies, Taylor, & Bourguignon, 2006; Millea & Holloway, 2000; Shapiro, Anderson & Danoff-Burg, 2005; Singh et al., 2006). Newer approaches to helping those with FM are support groups and online chat rooms (Hughes, Robinson-Whelen, Taylor, Swedlund, & Nosek, 2004; Skouen, Grasdahl, & Haldorsen, 2006). Many individuals benefit from discussing their life with FM with others in similar situations (Millea & Holloway, 2000).

Disease Activity Pattern and Subgroups

FM is an extremely complex condition that involves multifactorial aspects of physical and psychological functioning (Okifuji & Turk, 2002). Unlike RA that has distinct stages or progression, FM has no predictable patterns or progression (Reich, Olmsted, & Puymbroeck, 2006). Since not all FM patients experience the same symptoms, the syndrome does not follow a predictable course. Due to this huge variability in FM, researchers are beginning to look for subtypes or subgroups of FM patients that are based on psychosocial and behavioral characteristics.

Turk (2002) compared FM patients on physical functioning, perceived functional limitations, depressive moods, and quality of interpersonal relationships. Three distinct subgroups emerged: (1) Dysfunctional - this subgroup was characterized by high levels of pain, functional limitations, and affective distress; (2) Interpersonally Distressed – this subgroup was similar to the dysfunctional group, but members also perceived low level of

support from their significant other; (3) Adaptive Copier – this subgroup reported lower levels of pain and emotional distress and higher levels of perceived control over symptoms. FM patients were “roughly distributed equally within each of the three profiles” (Turk, 2002, p. 92).

Giesecke et al. (2003) grouped FM patients according to their pressure-pain sensitivity (hyperalgesia/tenderness), cognition, and mood. They identified three distinct subgroups. Group 1 (the smallest group) exhibited extreme tenderness, but had no identifiable cognitive or psychological factors that would contribute to higher symptom reporting. Group 2 (next largest group) had high amounts of pressure-pain and significantly high presence of mood and cognitive factors that may influence their symptom reports. Group 3 (more than half of the study sample) had moderate pressure-pain sensitivity and mood ratings and average cognitive factors. This discovery of FM subgroups suggests the need for more individualized treatment targeting the different characteristics of each patient (van Koulil et al., 2007).

Prognosis

The muscle pain and fatigue of FM is a chronic problem that waxes and wanes. Symptoms may improve, worsen, or stabilize and persist for years or over one’s life time (Baumgartner, Finch, Cedraschi, & Vischer, 2002; Buesing, 2005; Cronan, Serber, Walen, & Jaffe, 2002; Henriksson, 1994; National Library of Medicine, 2006). Early diagnosis and treatment of FM can reduce the severity of the symptoms (Hallegua & Wallace, 2005); currently, there is no cure for this condition (Bennett, 2007). Although FM is not a fatal illness, it does have a negative impact on one’s quality of life (Bennett, 2007; Birtane, Uzunca, Tastekin, Tuna, 2007; Buesing, 2005; Burckhardt, Archenholtz, Mannerkorpi, & Bjelle, 1993; Ofluoglu, Berker, Guven, Canbulat, Yilmaz, & Kayhan, 2005). The efforts of medical professionals, FM organizations and support groups, and individuals are

helping to improve the quality of life for people with FM.

After centuries of existence, FM finally is being recognized as a true disease. This is evidenced by the recent approval of the first drug to treat FM and the 2001 inclusion of FM in the National Institutes of Health (NIH) Fiscal Year 2001 budget. The NIH is committed to identifying the causes of FM, improving the daily lives of people with FM, and finding new strategies for treating this illness (Katz, n.d.).

Factors in the Development of Fibromyalgia

The root cause of FM still is unknown, but extensive research is being conducted in several areas. It is suspected that there are several interacting factors that are involved in the development of this illness. These may include:

Central Nervous System

People with FM have been found to have disordered central pain processing and sleep (Jones, Deodhar, Lorentzen, Bennett, & Deodhan, 2007; Millea & Holloway, 2000). A current theory, called central sensitization, states that people with FM experience pain because they have increased sensitivity in the brain to pain signals (Dworkin & Fields, 2005; McLean & Clauw, 2005; MFMER, 2007; Price & Syaud, 2005). This can be caused by abnormal levels of several different chemicals in the brain (Jones et al., 2007; Shiel, 2007a). Additional physiological abnormalities also have been found in FM patients such as increased levels of substance P in the spinal cord, low levels of serotonin and tryptophan, hypofunction of the hypothalamic-pituitary-adrenal axis, and low levels of blood flow to the thalamus region of the brain (Katz, Greene, Ali, & Faridi, 2007; Mease, 2005; NFA, 2007a; Stratz, Fiebich, Haus, & Muller, 2004).

Genetic Predisposition

Genetic and environmental factors may predispose people to FM (Ablin, Cohen, & Buskila, 2006; Clauw, 2007; Crofford, 2005). Estimates of FM mothers having children

affected by FM range from 28% to 70% (Buskila & Sarzi-Puttini, 2006). Children of mothers with FM “have approximately a 60% increase in odds of having a lifetime episode of major depression” (Raphael et al., 2004, p. 458). Findings presented at the International Congress of Neuroendocrinology on June 19-22, 2006 suggest that females born to mothers who were burdened or stressed during their pregnancies may be at a risk for FM (Rossi, 2006).

Trauma

A high percentage of people find that FM can be triggered by traumatic illness or injury particularly in the upper spinal region and neck (Hughes, 2006; Tishler, Levy, Maslakov, Var-Chaim, & Amit-Vazina, 2006). Yet, the role of whiplash trauma, often associated with the onset of FM, is debatable. According to Tishler, Levy, Maslakov, Bar-Chaim, & Amit-Vazina (2006), physical trauma is not a triggering event for FM. “Whiplash injury and road accident trauma were not associated with an increased rate of FM after more than 14.5 months of followup” (p. 1183). Severe traumatic experiences that occur in childhood (physical, emotional, or sexual abuse or emotional and physical neglect) also may be a factor in adults developing FM (Anderberg, Marteinsdottir, Theorell, & von Knorring, 2000; McLean, Clauw, Abelson, & Liberzon, 2005; Van Houdenhove & Luyten, 2006). Rates of childhood trauma in FM patients range from 32% to 64% (Weissbecker, Floyd, Dedert, Salmon, & Sephton, 2006). Childhood abuse also is associated with more severe physical symptoms (especially pain), greater psychological distress, poorer psychological adjustment, and greater functional disability (Davis, Luecken, & Zautra, 2005; Fillingim & Edwards, 2005; Weissbecker, Floyd, Dedert, Salmon, & Sephton, 2006). Sexual and physical abuse in women also is associated with FM (Bennett, Jones, Turk, Russell, & Matallana, 2007; Ciccone, Elliot, Chandler, Nayak, & Raphael, 2005; De Civata, Bernatsky, & Dobkin, 2004; Walker, Keegan et al., 1997).

Infection

Viral or bacterial infections may trigger FM. Researchers have found that Lyme disease, Epstein-Barr, parvo-virus, HIV, hepatitis C, mycoplasmas, *Chlamydia pneumoniae* are associated with a greater prevalence of FM (Ablin et al., 2006; Cruz, Catalan-Soares, & Proietti, 2006; Endersen, 2003; Machtey, 1997). Four to 7% of people with these infections develop FM (Clauw, 2007).

Personality

For more than two decades, researchers have been suggesting that there is a “fibromyalgia personality” and the idea still has not been abandoned. Amir et al. (2000) described FM patients as having “distinct personality characteristics, such as being demanding towards themselves as well as towards others. They are conscientious, committed, honest, well-organized, and have high moral standards” (p. 8). Other characteristics attributed to this personality are: depression, hypochondriasis, anxiety, hysteria, social introversion, harm avoidance, low novelty seeking, pessimism, perfectionism, catastrophizing, phobias, and panic attacks (Anderberg, Forsgren, Ekselius, Marteinsdottir, & Hallman, 1999; Buskila, Cohen, Neuman, & Ebstein, 2004; Ekselius, Bengtsson, & von Knorring, 1998; Kendall, Elert, Ekselius, & Gerdle, 2002; Sansone, Levengood, & Sellbom, 2004; Scudds, Rollman, Harth, & McCain, 1987; Trygg, Lundberg, Rosenlund, Timpka, & Gerdle, 2002). A few researchers have attributed some of these personality characteristics, such as anxiety and depression, to genetic predisposition (Buskila, Cohen, Neumann, & Ebstein, 2004; Cohen, Buskila, Neuman, & Ebstein, 2002). Other researchers, however, question whether these characteristics cause or are the result of FM.

Social Support of Fibromyalgia

Social support is crucial for those with FM. When compared to RA patients, FM patients considered their healthcare providers as intimate members of their social network and made fewer attempts to meet new people (Murray, Daniels, & Murray, 2006; Oliver, Cronan, Walen, & Tomita, 2001). In addition, the FM social networks were “closed networks within a small geographic area. These networks lacked initiative to establish and maintain relations, and [could] hardly fulfill the patient’s psychosocial needs” (Bolwijn et al., 1994, p. 46). Social networks for FM patients are more restricted than RA networks; yet, FM patients do not perceive themselves as being lonely (Bolwijn, Van Santen-Hoeufft, Baars, & Van der Linden, 1996; Davis, Zautra, & Reich, 2001; Schleicher et al., 2005).

In a study by Bernard, Prince, and Edsall (2000), FM support group members ranked social support received from various family members. Their significant other and children were ranked highest and female relatives were ranked higher than male relatives (cited in Schoofs et al., 2004). Montoya, Larbig, Braun, Preissl, and Birbaumer’s (2004) study on the effects of social support provided by the presence of a significant other showed that FM patients reported less pain and sensitivity to touch when their significant other was present.

Healthcare support is extremely important for FM patients and the quality of social support is important in determining illness outcomes in women with FM (Franks, Cronan, & Oliver, 2004). Therefore, having a physician who is empathetic, patient, knowledgeable, and understanding of the frustrations faced by those with FM is mandatory to help these patients cope with their illness. However, many FM patients do not feel that their physicians exhibit these qualities and some feel as though they are required to prove that they truly are ill. For those living with a chronic illness, a positive patient-physician relationship is crucial for a higher quality of life (Schoofs et al., 2004).

Controversies in Fibromyalgia

Over the course of the past 50 plus years, FM has provoked many controversies in the medical community. It would be remiss not to briefly discuss them here. FM often is referred to as a “mystery” disease because there is no known cause, standardized treatment, or predictable progression (Reich et al., 2006). Descriptions of this condition can be found in medical writings from more than four-hundred years ago; yet, as of 2007, many questions and issues still surround this illness:

1. Etiology: What causes FM? Is FM a psychosomatic or physical (somatic) illness? Is FM a manifestation of hysteria? Does FM cause depression or does depression lead to FM? Why are there no hard physical signs or laboratory evidence (Pearce, 2004; Powers, 1993)?
2. Diagnosis: Although in 1990 the ACR produced a set of criteria for classification of FM, this is not meant to be used as a diagnostic tool. What is the definition of FM? How can there be one definition when FM patients have a huge variety of symptoms and comorbidities? What criteria should be used to diagnose FM (Goldenberg, 1995)?
3. Treatment: Can a standard treatment be found? What works for one individual does not work for another, and therefore, the approval of Lyrica (pregabalin) for treatment of FM does not mean that all FM people will find relief, if they use it.
4. Acceptance: In 1986, Bennett stated that there was, “widespread acceptance of fibrositis by North American physicians” (p. 676). In 1990, Wolfe stated, “[o]ver the last decade [1980] fibromyalgia (fibrositis) has been transmogrified from a scientifically and clinically disreputable construct into a popular, accepted, clearly prevalent syndrome” (p. 681). In 1995, Goldenberg stated that some rheumatologists question the “very existence of fibromyalgia” (p. 3). “Fibromyalgia is thought to be such a society-driven disorder, an illness whose presentation is a metamorphosis of the distressed patient’s problem into one

that seems more like a ‘disease’ and thereby is more legitimate” (Ferrari & Russell, 2007, p. 62).

5. Disability: Wolfe (1997) warned that society must not encourage labeling FM patients as disabled. Yet, Goldberg (1999) asked whether pain can cause disability, and Robinson (2004) noted that FM patients are suffering and burdened by the cost of their disability.

6. Labeling of fibromyalgia as a disease: Will such labeling create a surge in those who collect disability payments? Labels of FM provide structure and understanding of the illness for patients. In 2004, Hadler and Greenhalgh stated that FM is one of the “most impenetrable and controversial labels in medicine today” (p.1) and with regard to FM, “[m]edicalization occurs whenever a set of social problems is reformulated as a medical problem” (p. 2).

In summary, as stated by Russell (2004), the medical community needs to find the cause(s) of FM, develop practical diagnostic criteria, find a common acceptable name, and establish effective treatment (s) for this illness.

Selected Theoretical Frameworks

Chronic illness is experienced on many levels and in many systems. Within the person, chronic illness produces biochemical changes in and across various physiological subsystems. As changes in the person’s functioning occurs, the family system is likely to experience shifts in roles, routines, and rules; and in the mother-child dyad, there may be changes in their relationship associated with the illness. An understanding of chronic illness and its effects is not complete unless one recognizes these various aspects of the illness and their interrelationships. The occurrence of chronic illness in a family member introduces a potential multitude of changes within the individual and family. Family systems and family development theories can be used as frameworks within which to study

these changes. Embedded in these theories are core concepts about the nature of change. Therefore, aspects from both of these theories will be used in this study to examine the effects of chronic maternal illness on children.

Family Systems Theory

History

Before the development of general systems theory, the world was viewed by scientists primarily through mathematical and statistical models. During the 1950s von Bertalanffy, a biologist, changed this approach by formulating a general systems theory (Broderick, 1993). His new theory defined systems as "set[s] of elements standing in interrelation among themselves and with the environment" (Bertalanffy, 1975, p. 159).

A system refers to a set of components linked to each other by organized, predictable patterns and interactions. Systems theory holds that no matter how much information is known about the individual parts, it is impossible to understand the system without also understanding how the parts relate or interact with each other (Rothchild, 1992). Interactions within the system allow events that affect one part of the system to resonate throughout the entire system. Systems theory offers a way of explaining a unit as it relates to itself and its environment.

Around the same time, two other theoretical frameworks emerged - information and cybernetics theories. Information theory primarily is concerned with communication - how messages are sent, processed, and received, whereas cybernetics theory is concerned with the "communication and manipulation of information in controlling the behavior of many kinds of systems such as physical, chemical, and biological systems, as well as families and other social systems" (Whitchurch & Constantine, 1993, p. 332). These three theoretical approaches intertwined and provided concepts for the development of social systems theory and the current dynamic systems theory of families. Family systems theory

incorporates concepts from ecology, biology, cybernetics, social science, and communication systems.

Family systems theory focuses on interpersonal and group processes and interaction, rather than on individual parts within the system. A critical aspect of this theory is that behavior by one family member influences and defines each and every other member of the family:

In family systems, any event that significantly affects an individual, such as the onset of a major illness, must also have an effect on that person's entire family system. The individual's response to the event will in turn be powerfully influenced by the family. How individuals and families affect each other will depend on the roles that each person plays within the family, the patterns of communication within the family, the family's rules for handling problems, and the flexibility of those rules. (Rothchild, 1992, p. 836)

Characteristics of Family Systems and Their Application to Chronic Illness

Wholeness/holistic aspect. Aristotle is credited with declaring that the whole is greater than the sum of its parts (Broderick, 1993). From a systems perspective, families and individuals are viewed holistically (as an entire unit) with attention to their interconnectedness rather than their separateness. "The interrelatedness of components in the family system gives rise to new qualities and characteristics that are a function of that interrelatedness" (Friedman, 1992, p. 118). When the family is viewed as a whole, it is greater than the sum of its parts (O'Connor, Hetherington, & Reiss, 1998; Whitchurch & Constantine, 1993). In family systems theory, the main focus is on the family as being unique with its own character, strengths, weaknesses, and communications style that is more than the sum of its individual members (Day, 1995; Roberts, 1987).

According to family systems theory, any event that significantly affects individual

family members also affects their entire family system. While chronically ill people must adapt to changes and loss, their families must adjust to the loss of the familiar person and learn to cope with “a new and frequently problematic individual” while assuming unfamiliar, new, and difficult roles (Bonder, 1986, p. 14).

The onset of a mother’s illness presents crises and challenges to the family system (Johnston et al., 1992; Sholevar & Perkel, 1990). Chronic illness produces and creates permanent change; the family balance is forever different (May, 1992). Families must find new ways to regain a sense of equilibrium as the family’s routines and roles are changed to accommodate the chronically ill mother (Patterson, 1988b). The roles of all family members may undergo frequent changes as the mother’s ability to perform her various functions fluctuates with remissions and exacerbations (Blackford, 1992). Role changes create shifts in the division of labor. Some of the previous responsibilities of the mother may be given to children. In turn, increases in children’s chores and household duties may decrease the amount of time they can spend on leisure activities or school work.

Within the past decade, health practitioners have recognized the importance of moving beyond an individual approach in chronic illness to include the entire family in the individual’s health regime (Cannon & Cavanaugh, 1998). This “innovative, holistic, family-focused perspective on the care of those with chronic illness” emphasizes the interconnectedness of families and individuals (Butcher, 1994, p. 70).

Interdependence and organization. A system is made up of interacting, interdependent parts. For these parts to maintain a consistent relationship, organization is required (Nichols & Everett, 1986). This is achieved through the structure of the system (the arrangement of its parts) and through the function of the system (activities engaged in that allow survival, continuity, and growth of the system).

Family systems experience reciprocal patterns of interaction. It is impossible for one

person in the system to change without affecting the remainder of the family members. When a family member becomes ill, the family structure is disrupted. "Disruption of the family's organizational structure may precipitate a crisis (Patterson & Garwick, 1994, p. 298). Unfortunately, with chronic illness, these disruptions are cyclical and never ending. Therefore, "coping with chronic illness is not an episode but an ongoing process" (Johnston et al., 1992, p. 228).

Family structure (organization) is provided through roles. There is a systems implication to family roles since family definitions depend on the existence of at least one other family person. For example, a wife must have a husband, a mother must have a child, and a sibling must have another brother or sister. Yet, every family member has his/her own unique role or function that is developed through interpersonal transactions (Jacobvitz & Bush, 1996; Rosenblatt, 1994). While these roles are not static, they still exhibit a predictability or constancy.

Historically, women have been identified as the family's primary caregiver. This pattern continues today. "Many women in this society will spend the majority of their adult years caring for family members: children in the first half, followed by aging and ill parents and spouses in the second half" (Strozier, 1996, p. 259). When a mother becomes chronically ill, a role change may be necessitated. In turn, this requires complementary role changes in other family members (Friedman, 1992). Therefore, chronic illness in the mother may have a direct impact on the family's stability. If she is unable to fill the role of caretaker, then some family member who may be unfamiliar with this role needs to take over. Some disorganization in the family may then occur (Turk & Kerns, 1985). If she also has been the "main breadwinner", the entire survival, continuity, and growth of the family can be threatened. Role changes come with a cost to the involved individuals since the loss of any of these roles may represent a loss of power, status, finances, mastery,

competence, and/or contribution (Eberhardt et al., 2007; Goodheart & Lansing, 1997; Toombs, 1993). “When illness results in the vacancy of critical roles the family often enters a state of disequilibrium until new homeostasis is achieved” (Friedman, 1992, p. 227).

Self-regulation. Although there are fine distinctions between the terms self-regulation, steady state, and equilibrium, they are used rather interchangeably to describe how a system responds to processes of change. Through self-regulation, the system works at controlling and balancing its input and output via a feedback loop. Confluence, steady state, or equilibrium is the result of a system being in balance. However, this balance is not static. There is continuous exchange of information between the system and its environment (Hinde, 1989). The primary motivating factor in a family’s response to change is the maintenance of stability (Kerns & Weiss, 1994).

Morphogenesis is defined as the ability of the system to change and develop in a positive manner. When families are faced with a new situation, they must be innovative and creative in solving problems and developing new strategies and approaches (Whitchurch & Constantine, 1993). Morphogenesis is required for families to change their rules and responses to each challenging situation.

Morphogenesis is counterbalanced by the principle of morphostasis - the system’s ability to stabilize or return to a state of equilibrium. Too much or too little change is resisted by the family structure. Each family must find its own element of stability that is neither too rigid or too chaotic. This helps them return to an acceptable steady state.

In a family where the mother is chronically ill, equilibrium may be difficult to achieve. Coping with the demands and uncertainty associated with maternal chronic illness, the family system may find itself continually readjusting (Eriksson & Svedlund, 2006; Stetz, Lewis, & Primomo, 1986). With chronic illness, mothers may be available one day but not

available the next. Given such uncertainty, disequilibrium is likely to be frequent (Boss, 1986).

Boundaries. Boundaries can be defined as "a border between the system and its environment that affects the flow of information and energy between the environment and the system" (Klein & White, 1996, p. 158). The amount of permeability of the boundary helps define the system. For example, the less porous the boundary, the more isolated or closed is the system. In family systems, this concept is mainly metaphorical.

An open system refers to the degree of interaction that a system exhibits with its surrounding environment or the exchange of information and other material with the environment. This interaction is necessary for the survival of the system. The degree that a system is open determines the amount of interaction and influence that can occur with outside elements such as other individuals, groups, extended family, friends, colleagues, and community (Jones, 1993). "The family's perception of who is inside or outside the family system is significantly related to the interaction within that system as well as between that system and the outside world" (Boss, 1980, p. 445).

To survive, all systems must receive input from their environment. Input enters the system in the form of information, energy, and material which is processed by flowing through the system and is released by the system as output. When there is an underflow of information into a family system, the family is considered to be relatively closed. This threatens its stability. However, families with a constant flow of information into their systems may become disorganized and chaotic. "In the healthy family, boundaries adequately screen information input and output. When an excessive amount of information flows into the family, the boundaries are closed, and when an underflow of information occurs, the boundaries are opened" (Friedman, 1992, p. 120). Healthy boundaries are flexible, but have some definite limits - firm enough so one's priorities and

values remain clear, but closed enough so outside assaults can be withstood; and distinct enough to allow individuality, but sufficiently open to permit new ideas and perspectives (Forrest, n. d.).

"Open systems are characterized by the concept of *equifinality*, or the ability of a system to achieve the same goals through different routes" (Whitchurch & Constantine, 1993, p. 334). Equifinality is found in family systems as well. Family/individual goals (such as seeking relief from chronic illness symptoms or lessening added burdens on family members) can be attained through a variety of different methods.

A closed system interacts minimally with its environment. A true example of this has never been found because total noninteraction implies that the system is dead. However, there are varying degrees of openness in systems. A family that maintains a very low exchange of information and interaction with other systems (e.g., school, workplace, church, health providers), is described as a relatively closed family system (Nichols & Everett, 1986).

Since the nature of chronic illness is that it cannot be cured and may not improve, frequent reciprocal exchanges of information between the individual, family and medical sources outside the family are required. If flare ups of chronic illness are frequent and the person requires close attention, the constant change in illness demands may keep the family focused internally. Such a family may become a relatively closed system (Papadopoulos, 1995).

Internal family boundaries can be used to divide the family unit into smaller units or subsystems such as parental, sibling, parent-child, and spousal (Kerig, 2005). They may consist of "an individual or any combination of individual members that is less than the whole family system" (Roberts, 1987, p. 59). Identification of subsystems is based on what they do and who participates in them. This is important when trying to determine

how the family works and where the alliances reside. “Family systems theorists emphasize the importance of parents maintaining clear boundaries with their children such that the parent is responsible for nurturing and supporting their child rather than relying on the child for support” (Leon & Rudy, 2005, p. 112).

When a mother becomes ill, changes in family boundaries are likely to occur. During the ensuing process of reorganization, boundaries can become ambiguous. Boundary ambiguity can be defined as the family not knowing who is in or out of the family due to either physical or psychological absence (Boss, 1986; Boss, 1992; Boss, 2007; Buehler & Pasley, 2000; Hobfoll & Spielberger, 1992; Pasley, 1994; Rosenblatt, 1994). Mothers with chronic illness can be physically and/or psychologically absent from their families. This loss of a family member increases the amount of family stress. According to McLeod (1991), children who experience parental loss also are at a higher risk for depression in their adult years. “When family members cannot obtain clear facts surrounding their loss, the system is frozen into place; structural reorganization is blocked; systemic boundaries cannot be maintained. Individuals remain immobilized until they are able to construct a new reality of who is in and who is out of their family” (Boss, 1992, p. 113). According to Boss (1991), despite the added pressures of chronic illness on family members, boundaries must be maintained for the family system to survive:

The higher the boundary ambiguity in the family system, the greater the helplessness (low mastery) and the greater the likelihood of individual and family dysfunction (depression and conflict). Boundary ambiguity can result from the outside world not giving the family enough information about the event of loss *or* it can arise inside the family from its own denial of the loss. In either case, the ultimate indicators of who is in and who is out of the family are based on the family’s collective perception, as well as individual perceptions, and most important, on the congruence among family

members' individual perceptions. (p. 167)

If there is a persistent, high degree of boundary ambiguity, the family is at risk of becoming highly stressed and dysfunctional. Chronic illnesses with uncertain progress and outcome create a higher degree of family ambiguity than those that are more predictable and treatable (Boss, 1992).

Hierarchy of systems. Systems have many levels of components; the more complicated, higher levels are composed of simpler, more basic levels. Living systems may be broken down into simpler to more complex levels such as cells, organs, organisms, groups, organizations, societies, and supranational systems. The family system can be conceptualized as the simpler individual, spousal, parental, and sibling subsystems; the more complex nuclear family system; and the even more complex intergenerational system (Nichols & Everett, 1986).

Family systems theory states that families interact with other systems. Some potential systems are listed in descending order: biosphere -> society-nation-> culture-subculture -> community -> family -> two-person -> person (experience and behavior) -> nervous system -> organs/organ systems -> tissues -> cells -> organelles -> molecules -> atoms -> subatomic particles (Goodheart & Lansing, 1997; Patterson & Garwick, 1998). Since illness is part of an individual, it must be included as a component of the individual's system (Leventhal, Leventhal, & Nguyen, 1985; Rolland, 1987b; Rolland, 1988; Rolland, 1998).

As Coyne (1995) stated, “[f]amily systems theory is an invaluable conceptual framework for understanding illness in close relationships” (p. 98). It explains the interconnectedness and interactional context of the family as members attempt to meet the challenge of chronic illness.

Family Development Theory

History

Since its introduction in the early 1900s, family development theory has moved through three distinct phases. During the Great Depression years, rural sociologists, demographers, and economists studied the impact of poverty on families and its application to social policy. The terms "family life cycle" and "family development" first appeared in their publications. These researchers' interests in the sociodemographics of marriage, reproduction, household structure, and employment histories led to the idea of stages in the family life cycle. This was the first phase of family development theory.

During the 1970s, Rodgers suggested abandoning the family life cycle concept and adopting the family career approach. According to Rodgers and White (1993), "family career becomes the sequential linking of family stages over the life history of the family system" (p. 238). It is composed of all the events and periods of time (stages) between events that a family travels (Klein & White, 1996). The conscious attempts to develop the theory and the introduction of both a life course perspective and the concept of family career marked the second phase of family development theory.

Since the 1980s, scholars have been re-examining family development theory. Arguments have ensued over the level of analysis. Aldous argued that the major difference is that the life course approach is focused on the individual and the family development approach is focused on the family. According to her, neither approach deserves to be called a scientific theory (Klein & White, 1996).

However, White and Rodgers believe that the family development perspective is a theory. They have attempted to answer critics by revising and simplifying concepts (such as change, family, role, stage) and developing formal propositions for the theory. In summarizing the history of family development theory, Klein and White (1996) noted:

The theory has gone through three phases of maturation: a descriptive phase in which the stages of the family life cycle were used to study families; a systematizing phase in which the theory received its first conscious statement as a theory; and an ongoing, formal phase in which, as a response to criticisms and new methodologies, the theory has been formally stated as propositions and formal models. (p. 123)

White further described family development theory as being concerned with “delineating patterned changes in families across time and [he] therefore emphasizes dynamics” (Nichols & Pace-Nichols, 2000, p. 12).

Currently, the approach in family development theory is to acknowledge that individual development is important, but to stress that the main focus is on the development of families as interacting groups of individuals who are organized by social norms (Nichols & Pace-Nichols, 2000). The main interest of family development theory is change in family dynamics over time (Olson & Lavee, 1989). In the past, family developmentalists did not differentiate between change and development. Today, many developmentalists accept a sociological definition that "family development is a process following age- and stage- graded social norms" (Klein & White, 1996, p. 127). Family development theory contains several basic concepts which are not unique to this theory as they have been used by sociologists in other areas of study (Newbrough, Simpkins, & Mauer, 1985). However, in this theory, these terms are used to "emphasize the structural aspect of the family" (Rodgers & White, 1993, p. 231).

Characteristics of Family Development and Their Application to Chronic Illness

Norms and roles. Norms can be defined as common behavior expectations and rules held by members of a group which govern both the group and individuals; norms are the basic structural building blocks for the family "group". They can reflect expectations of the way something is to be accomplished at a specific stage in the family or at a specific

age of an individual. Therefore, norms often are age- and stage- related.

Roles are all of the norms (behavior expectations/rules of the social group) attached to an individual's kinship position. Norms, and therefore roles, change over time. It is typical for norms and roles to change with a person's age and structure of the family. Family roles are related to the organizational structure and division of labor in the family. Typical family adult roles can include: child socialization, child care, financial provider, housekeeper, and/or sexual, therapeutic, and recreational provider (Johnson, 1988).

People also occupy role positions that can be defined as all of the roles that are applicable to a person at one point in time. Since families traditionally are imbedded in a kinship structure that is defined by gender, marriage or blood, and generational placement, basic family positions can include husband, father, son, brother, and wife, mother, daughter, and sister (Klein & White, 1996).

When illness strikes a mother during the child-rearing phase, it is occurring earlier in the life cycle than expected. Since the ability to meet normal individual and family goals can be thwarted, serious strains can be placed on family functioning (Rolland, 1999). The mother's roles of nurturing and caretaking may need to be assumed by other family members who are unfamiliar with them (Lewis, Woods, Hough, & Bensley, 1989; Litman, 1974). Significant stress can occur during these role transitions through role confusion, unhappiness, and anxiety (Friedman, 1992). "When children prematurely adopt adult roles, they do not have the opportunity to progress through age-normative transitional and developmental experiences, and their adult functioning as parents may be compromised" (Locke & Newcomb, 2004, p. 121).

Stages, events, and developmental tasks. According to family development theory, families move through stages of development. A stage can be defined as a segment of time when the structure of the family and roles of family members are distinct from time

periods prior to or after it. Movement to another stage requires an event that creates a change in the membership or organization of the family. Events are important occurrences in the family that produce change at a specific point in time. Chronic illness can be classified as an event which produces permanent change (May, 1992).

During each of the stages, developmental tasks - sets of norms (role expectations) performed at specific stages - are expected to be achieved. This concept was important during the life-cycle phase of family development theory. During each stage of the life cycle, specific tasks were to be accomplished for the survival of the family. Today, some researchers believe that this "concept is redundant with the age- and stage-graded notions of norm and role and [they] no longer include it among the core concepts of the theory" (Klein & White, 1996, p. 129). However, chronic illness does affect family relationships and the achievement of developmental tasks (Cannon & Cavanaugh, 1998; Pedersen & Revenson, 2005; Rankin & Weekes, 1989).

This study will concentrate on the interaction of chronically ill mothers and their adolescent children. Therefore, family development concepts of stages and developmental tasks appropriate for these periods will be reviewed.

Adolescence can be defined as the period between childhood and adulthood that involves certain social, biological, and cognitive changes. For most individuals, adolescence begins with early adolescence (10-13 years of age), moves toward middle adolescence (14-17 years of age), and ends with late adolescence (18-22 years of age) (Hendren, 1990). During this time, the range of biological, cognitive, and social changes moves from "the development of sexual functions to abstract thinking processes to independence" (Santrock, 1993, p. 29). This stage often is viewed as one of the most turbulent as adolescents struggle for autonomy and independence, develop a stronger peer social network, and forge a new role and identity (Borduin & Mann, 1988; Goodheart &

Lansing, 1997; Hendren, 1990). Developmental tasks are centered around moving the individual from childhood to independent adulthood (Jepsen & Dickson, 2003).

[T]he developmental tasks of adolescents include accepting and learning to effectively use their changing body [*sic*], achieving a satisfying and socially acceptable sex role, developing more mature relationships with peers, achieving emotional independence from parents and other adults, establishing an identity as socially responsible, developing intellectual skills and social sensitivities necessary for civic competence, and preparing for marriage and family life. (Hymovich & Hagopian, 1992, p. 47)

Adolescents' concerns about their place and function in society create additional stress. They worry about meeting personal goals, self-esteem, changing values, social standards, personal competence, abilities, and personal traits (Humphrey, 1998). Young adults' overall goal is independence. Devaluing parents helps them loosen their dependent ties. They must partake of educational or vocational preparation so they can become career ready and meet economic responsibilities (Brummel-Smith, 1994). Under normal circumstances, adolescence is a relatively unstable stage of life. This stage is even more difficult when adolescents also have to deal with chronically ill parents.

Many challenges face families with teenagers as both parents and children develop as individuals (Canary, Cupach, & Messman, 1995; Rankin & Weekes, 1989). As adolescents mature and seek more autonomy, the main family developmental task is to determine how to balance freedom with responsibility. While teens increasingly explore more of their world outside of the family, redefining boundaries becomes a continual process (Burt et al., 2005). Relationships between parents and adolescents progressively change as teens move from "dependence on and control by the parents and other adults, through a period of intense peer group activity and influence, to the assumption of adult roles" (Friedman & Miller, 1992, p. 93). Considerable friction, mistakes, and crises may

be common in this stage.

At the same time, parents also are struggling with their own developmental tasks. Major system changes are occurring due to the new roles and norms wrought by adolescents. Parents of adolescents often are middle-aged and may be experiencing personal midlife crises; they are reassessing personal goals, reviewing successes and failures, and examining the direction their lives are taking. They are becoming more aware of the fragility of health and the decline of physical attractiveness (Berman & Napier, 2000; Macionis, 1987). This often is extremely stressful since these are greatly revered in our society.

According to Carter and McGoldrick (1989), for positive development to proceed in families with adolescents, there are specific changes required: (1) shifting of parent-child relationships to permit the adolescent to move in and out of the system, (2) refocusing on midlife marital and career issues, and (3) beginning shifts toward caring for the older generation.

If a mother develops a chronic illness during her child-rearing years, further revisions of one's life is needed. The illness becomes part of her own personal system and it is essential to recognize the reciprocal impact of the mother's chronic illness on the remainder of the family members. Rankin and Weekes (1989) stated:

In middle-aged families with adolescents where a member has a chronic illness, decreased family unity and cohesiveness affect achievement of family and individual developmental tasks. ...[T]he changes in roles that occur in families where members have major disabilities may affect cohesiveness to such an extent that achievement of developmental tasks is delayed for all family members. (p. 17)

Transitions. Transitions occur during shifts from one qualitatively distinct family stage to another family stage. A family's career consists of many transitions between stages.

When viewed over time, family transitions are seen as paths taken and not taken. They could be viewed as many branches on a tree with a series of branches depicting one family's path. Family transition combines the concepts of stage, event, and time.

"Transitions from one family stage to another are indicated by the events between the stages" (Klein & White, 1996, p. 129). Transitions are marked by events and events are used to signal the beginning or end of a stage. However, events do not indicate what the next stage will be. There is no normative family stage sequence. The order of events and stages can vary.

Family stress is often greatest at transition points when moving from one stage to another (Carter & McGoldrick, 1989). During these transition periods, all levels of the family are in greater flux and changes in roles and family interactional patterns occur. "...[T]ransition periods are potentially the most vulnerable because previous individual, family, and illness life structures are reappraised in the face of new developmental tasks that may require discontinuous change rather than minor alterations" (Rolland, 1987b, p. 493). If the onset of chronic illness coincides with a transition period, serious disruptions in the family can take place.

Parentification

History of Concept

Throughout the history of family life, parents have expected and demanded adult-like behavior from their children (Jurkovic, 1997). Prior to the late 18th and early 19th centuries, the blending of child and adult worlds for social and economic reasons was common. Preformationism, a predominant theory during the Middle Ages, viewed children as miniature adults. By the ages of six to seven, they physically and socially were considered adults (Crain, 1992). Therefore, the concept of a "parental child" actually was a historical norm. The failure to recognize and delineate childhood as a separate stage of

human development continued for several centuries and it allowed various abuses of children, particularly physical abuse, abandonment, and excessive child labor.

In the early 1800's, separation of childhood from adulthood occurred. Over the course of the next two centuries, childhood increasingly became a period of carefree happiness with few responsibilities. Children changed from being contributors to their families' and communities' social and financial well-being to being non-contributing members of their society. By rendering its children economically valueless in family and community life, to some extent the United States and other highly industrialized nations made children and childhood a liability. Even though a huge number of economically disadvantaged children are excluded from this scenario, "their expendability is exhibited in high rates of accidental injury and death, violence, substance abuse, and gang involvement" (Chase, 1999, p. 24).

In more recent history, while child labor and abuse laws and developments pertaining to children in areas of legislation, education, medicine, and social services have begun to address the needs and rights of children, changes in the postmodern American family have increased the need for children to assume additional responsibilities (Jurkovic, 1997).

Jurkovic (1998) stated:

For example, the rates of cohabitation, divorce, single parenting, out-of-wedlock births, and homeless families have risen significantly. Moreover, the traditional two-parent family, which once was the norm, is overtaxed emotionally and economically and is struggling to survive, frequently without the benefit of extended family ties.

Deteriorating neighborhoods, joblessness, inadequate social services, and insufficient resources for diverse family forms are further stranding parents and couples in U.S. society. As a result, children are increasingly being called upon to serve as a primary support system for their parents, siblings, and families. (p. 237)

This situation is known by a variety of terms such as role reversal, parental child,

hurried child, hero-child, overachiever, underachiever, adult-child, overburdened child, young carer, pseudoadult, generational boundary dissolution, spousification, family healer, and parentification (Chase, 1999; Jurkovic, 1998; Shaffer & Sroufe, 2005; Teyber 1992; Ward, n.d.).

Over the past few decades, the concept of parentification has been the focus of several theorists. Schmeidler, in 1948, was one of the earliest theorists to present the concept of parent/child role reversal. He noted that some degree of infantile level development is present in all adults. Those adults who were deprived of earlier interpersonal relationships may exhibit stronger and more compelling infantile needs. As parents, these emotionally deprived people may unconsciously rely on their children to be parental figures. In 1956, Mahler and Rabinovitch reported that children may assume a variety of roles to strengthen unstable marital and family ties. This becomes destructive if the child's normal emotional and social development is impeded. In 1965, Anna Freud observed that when there is a loss of a parental figure due to divorce, children often fill the vacated role (Chase, 1999; Goglia, 1982).

Minuchin, Montalvo, Guerney, Rosman, and Schumer (1967) made similar discoveries while working with families of delinquent youth in New York City ghettos. Due to the absence or underfunctioning of the fathers, many children had assumed the roles of parent. These children were responsible for child-rearing and other parenting functions and were labeled "parental children" by the researchers. While past descriptions of parental children emphasized negative aspects for the child, this research introduced a more positive aspect for children. Minuchin developed standards for problematic and non-problematic parentified children. Parentification was acceptable if: (1) parental responsibilities were shared by more than one sibling, (2) responsibilities were age appropriate, and (3) children received support and recognition for their part in the caretaking of the family.

Parentification was not acceptable if parental children did not receive support from adults in performing the responsibilities and if the family power structure and adult-child boundaries became too ambiguous.

Further research by Minuchin and his colleagues (1967) recognized parental children in other families as well. The inappropriate roles of these children violated the boundaries of parental and sibling subsystems. In turn, this led them to not being fully accepted in either subsystem.

Boszormenyi-Nagy and Sparks (1973) are credited with first using the term “parentification” to describe a component of all personal relationships - healthy or unhealthy. Parentification occurs when there is “the subjective distortion of a relationship as if one’s partner or even children were his parent” (Boszormenyi-Nagy & Sparks, 1973, p. 151). Parentification, to some extent, is natural and inevitable in all parent-child relationships. It can contribute to healthy development of the child when it is a temporary and occasional event because it “helps prevent the parent from becoming emotionally depleted and allows the child to identify with responsible roles for his or her future” (Karpel, 1976, p. 2). Parentification is harmful when it interferes in the development of the child, occurs over a long period of time, is not acknowledged by the recipient, and does not meet the needs of the child (Walsh, 1998).

During the 1980s, researchers from Georgia State University became interested in parentification. Their work has provided much of the current information on this topic, including parentification as it is related to alcoholism, divorce, AIDS, workaholism, shame-proneness, self-esteem, career choice, long-term effects, and clinical treatment of parental children and their families (Chase, 1999; Chase et al., 1998; Godsall, 1995; Goglia, 1982; Jurkovic, 1997; Jurkovic, Jessee, & Goglia, 1991; Jurkovic, Thirkfield et al., 2001; Robinson, 2001; Robinson & Chase, 2001; Wells, Glickauf-Hughes, & Jones, 1999;

Wells & Jones, 2000).

Definition of Parentification

In healthy families, parents assume the responsibilities of nurturing and guiding their children. Clearly defined intergenerational boundaries are present which delineate specific roles and responsibilities of adults and children. The parent(s) perform family leadership functions, make decisions and plans for the family, enforce rules and limits for the children, provide an organized household with predictable routines, and seek companionship and support primarily from same-generational peers rather than from the children (Teyber, 1992; Godsall, 1988).

Parentification is a natural characteristic of family life. In some “immigrant and minority families where interdependence is a real strength and all members are expected to contribute to the family”, parentification is expected of the children (Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005, p. 883). It occurs in various forms within families and it does not always lead to negative outcomes in children. Responding to parental needs can be healthy because it helps children develop sensitivities to the needs, feelings, and expectations of others (Chase, 1999; Jurkovic, Morrel et al., 2001). If children’s parental responsibilities are fair and appropriate, then children “might find this role a bolstering, competence building one” (Chaney, 2002, p. 45). Jurkovic (1997) stated that “in the process, [children] often learn important social skills related to responsibility, independence, empathy, nurturance, and fair give-and-take in relationships” (p. 50). In turn, this can foster development of a healthy sense of identity and self-esteem (Karpel, 1976).

In healthy family systems, children are likely to practice parent roles since this is what they most frequently observe. For example, an older sibling may direct a younger sibling in some chore (Brock & Barnard, 1999). This is a normal part of the child’s maturation

process and is a healthy form of parentification. Jurkovic (1997) stated:

As a result of enacting a parental role, youngsters may... also gain trustworthiness and satisfy their needs to express caring and affection. ...[T]he occasional reversal of their roles provides youngsters with an opportunity to master socialization skills and to rehearse future role activities. (p. xiii)

Problems occur when adult and child roles are not clearly defined, boundaries are blurred between the adult and child generations, and too many of the adult personal needs are met by the children (Teyber, 1992). When children assume too many adult roles (such as family caretaking and emotional support) before they are emotionally or developmentally able, they become parentified. Children become parents to their own parents and provide care to them and/or other family members to the detriment of themselves. They fulfill the parental role in the family system (Barnett & Parker, 1998; Caroll & Robinson, 2000; Peris & Emery, 2005).

All families, especially during times of crisis and stress, place “overfunctioning demands” on their children (Chase, 2001). During these times, parent-child roles may temporarily become less well-defined. In particular, children of parents with chronic illnesses may experience these changes. The roles of all family members “undergo frequent changes as the parent’s capacity to perform previous functions fluctuates in remissions and exacerbations” (Blackford, 1992, p. 50). These unpredictable changes may lead to a blurring of boundaries between parent and child. When children assume too many of the parent’s responsibilities or meet too many of the parent’s emotional needs, role reversal or parentification occurs (Teyber, 1992). Parentification becomes unhealthy when children assume the role of parents to their own parents, forfeiting their personal needs for comfort, guidance, and attention (Godsall, 1995; Robinson & Chase, 2001). Other factors such as poverty, single-parent households, large families, or parental illness

also may affect parent-child functioning (Jurkovic, 1997).

Types of Parentification

Jurkovic (1997) identified four major prototypes of parentification: (1) destructive parentification, (2) adaptive parentification, (3) non-parentification, and (4) infantilization. He suggested that parentification can be thought of as a continuum, with destructive parentification, adaptive parentification, healthy non-parentification, and infantilization as major markers. This view of parentification “provides a context for interpreting the process of parentification” (Winton, 2003, p. 51). Since all children are parentified to some extent, all of them fall somewhere along this continuum line.

Destructive parentification occurs when children assume caretaking responsibilities that are not age-appropriate, not supported by family members, and violate generational boundaries. Earley & Cushway (2002) explained that healthy functioning of families and their members requires clearly defined boundaries. When children are expected to act as mates and/or parents to their parents, the family balance is upset and the individual’s growth and development is compromised. “An important criterion for destructive parentification is the way that parents and children interact... . Withholding acknowledgement of a child’s help, coupled with guilt inducement, is an effective and damaging form of manipulation” (Ward, 1999, p. 3). According to Chase (1999), detrimental parentification occurs when children’s normal developmental sequence of attachment, separation, and self-definition or identity is interrupted. Wells & Jones (1999) noted that parentified children attempt to bolster their parent’s self-esteem by shaping their own personalities to match the expectations of their parents. Jurkovic, Morrell et al. (2001) stated:

whether parentification becomes destructive depends on the balance of give-and-take in the family. An imbalance develops when the beneficent activities of children ...are not

acknowledged, legitimized, and reciprocated in the family, and the larger sociocultural context in which they live. Destructively parentified children often grow up in families plagued by substance dependence, workaholism, parental mood disorders, divorce, marital conflict, poverty, and other stressful conditions. They are at risk of suffering from various short-and long-term problems, for example, depression, anxiety, low self-esteem, and overfunctioning in relationships. (p. 130)

Adaptive parentification is said to occur when parents ask their children to contribute to the family's well-being, especially during a time of crisis or stress such as illness. This positive form of parentification is time-limited, not emotionally or physically overtaxing to the child, and is acknowledged or supported by the parents (Byng-Hall, 2002; Chase, 2001; Jurkovic, 1997). Because of this, children are able to provide caretaking for their family "without their personal identity being defined by their caretaking role" (Ward, 1999, p. 3).

Non-parentification is a healthy process where children are expected to assume a moderate level of age-appropriate family responsibilities. Their efforts are acknowledged, supervised, and reciprocated, and boundaries are maintained (Jurkovic, 1997; Winton, 2003). Parents are a trustworthy source of affection and support (Jurkovic, Morrell et al., 2001). This form of healthy parentification allows the child to develop a sense of competence, identity beyond that associated with the caretaking role, belonging, and trust and mutuality in relationships (Chase, 1999).

Infantilization refers to children who are developmentally underchallenged by their parents. Minimal, if any, responsibilities are required of them. Parents excessively meet their needs. Yet, like destructively parentified children, they experience boundary violations. These children are at risk of assuming an underfunctioning role in life (Jurkovic, 1997; Ward, n.d.).

Characteristics of Parentification

Intergenerational Perpetuation of Parentification

Family systems theory suggests that “adult patterns of interaction have their roots in the family of origin” (Robinson, 1999, p. 60). One of the primary aspects of parentification is that it is an intergenerational family dynamic. Boszormenyi-Nagy and Spark (1973) used the term parentification to describe intra- and cross-generational processes that typically occur over three generations. Parentification occurs because of generational boundary distortions (lack of clearly defined generational boundaries or subsystems in a family) where children become parents or mates to their parents (Chase, 1999; Goglia, Jurkovic, Burt, Burge-Callaway, 1992). Jacobvitz, Riggs, & Johnson (1999) noted that “boundary disturbances generally can be characterized as a parent’s failure to respect or encourage a child’s autonomy, becoming overly involved, controlling, or intrusive, and even expecting the child to care for the parent” (p. 36). These inappropriate alliances upset the balance in family systems and compromise growth and development among family members (Earley & Cushway, 2002). Boundary disturbances may lead to children’s development of social-emotional problems, internalizing and externalizing behavior, as well as anxiety, depression and low self-esteem in adolescence (Hazen et al., 2005).

Needy parents often are “individuals who did not have their own dependency needs met in their families of origin. These needy parents... may attempt to get their needs met in their families of procreation, by enlisting their children to take care of them” (Wells et al., 1999, p. 64). In turn, when these parentified children become adults, they are at risk of perpetuating the same relationship patterns (Bryant, 2006; Chase, 1999). Psychological autonomy in children, one of the central tasks of parenting, is thwarted by parentification (Zeanah & Klitzke, 1991).

Byng-Hall (2002) proposed that the parentification cycle can be broken if needy parents have secure relationships with their spouses. ..."[A]n insecure parent might feel sufficiently looked after in the marriage to be able to parent well. ...This helps to guard against a parent in need having to turn to a child in a crisis" (Byng-Hall, 2002, p. 381). The intergenerational transmission of destructive parentification could be thwarted or interrupted by increasing the mutual support between adult family members.

Object of Parentification and Sex of Child

Parentified children primarily assume responsibility for their mother, father, and/or one or more siblings. "The effects of destructive parentification possibly vary as a function of the primary object of concern and the child's gender. For example, same-gender parentification between parent and child (mother-daughter, father-son) may differ from cross-gender parentification (mother-son, father-daughter)" (Jurkovic, 1997, p. 9).

When parentification exists between mother and daughter, the daughter may develop an identity that reflects her parents' expectations and values with regard to relationships and career. She is less likely to explore or question new and different directions from her parents. Mother-daughter alliances are associated with higher anxiety for daughters. When there is father-daughter parentification, the daughter is even less likely to develop an independent identity. Daughters who fulfill a companion or confidant role (surrogate spouse) to their fathers exhibit severely low levels of commitment to careers or relationships. Furthermore, they have been found to experience more depression, anxiety, and low self-esteem (Chase, 1999).

Parentified mother-son relationships often result in reversal of the parent-child role or treating their sons as spouses, including inappropriate touching and flirting. Sroufe and Ward (as cited in Lazicki-Puddy, 2001) noted that mothers' self-reported history of sexual and/or emotional exploitation by their fathers often is linked to their seductive behavior

toward their sons. The result is that “sons with a history of mother-son role reversal and spousification were less popular with peers during preadolescence and more often violated gender boundaries on the playground (Chase, 1999, p. 45). Less is known about father-son parentification relationships. Jacobvitz et al. (1999) have theorized that fathers may parentify their sons differently than mothers parentify their daughters. While they noted that more research is needed to explore father-son role reversal, they suggested

[p]erhaps fathers expect sons to take on major household responsibilities, such as holding a job at a younger age, attempt to live vicariously through their sons’ athletic and academic achievements, and even encourage their sons to engage in sexual experiences at an early age. (p. 40-41)

When parentification involves emotional caretaking and child care, female children are more likely to assume these tasks and they may acquire more extreme traditional, feminine gender roles (Altschuler, Dale, & Sass-Booth, 1999; Jurkovic, 1997; Riedel, 1998; Wolkin, 1985). In families where mothers were ill, overwhelmed with childcare burdens, or disabled, fathers did not assume the nurturing parent role. The burden of the mother’s unfulfilled duties often were taken over by the oldest daughter (Herman & Hirschman, 1981). By assuming the responsibilities inherent with sex-role expectations, daughters’ self-esteem may be bolstered (Wolkin, 1985). However, since their sense of identity revolves around the needs of other family members, they may identify themselves as caretakers to the exclusion of experimenting with alternative roles. For male children, emotional caretaking and child-care duties may encourage a more androgynous orientation (Jurkovic, 1998). Also, Jurkovic (1997) noted that it is less emotionally upsetting for boys to be involved in their parents’ difficulties.

Type of Role Assignments

Parentification literature has identified two forms of parentified roles that children

fulfill in families - instrumental and expressive or emotional (Jurkovic et al., 1991; Peris, 2006; Wells & Miller, 2001). Each role assignment has different demands and role behaviors. “When parentified roles are expected from children, the children usually will do their best to fulfill them *even if they are impossible*, thereby damaging themselves and others in the process” (Coale, 1999, p. 139).

Instrumental role assignment occurs when children become responsible for concrete functional tasks that physically maintain and support their family. Examples of instrumental tasks are: child care, cooking, grocery shopping, cleaning, earning income, and providing nursing care to an ill or disabled parent or family member (Jurkovic, Kuperminc, Sarac, & Weisshaar, 2005).

Expressive role assignment occurs when children attend to the family’s socioemotional needs. Examples of expressive parenting tasks undertaken by children are serving as a parental confidant, mediating family conflicts, acting as surrogate mate, protecting family members, and supporting, comforting, and nurturing family members (Chase et al., 1998; Jurkovic, 1997; Jurkovic, Thirkield et al., 2001). Jurkovic et al. (1991) suggested that expressive roles may be more detrimental than instrumental roles to the parentified child.

Often the line between these two forms of parentification roles is blurred. While children may perform one or the other role assignment, they also may perform both instrumental and expressive tasks in the family (Jurkovic, 1997). However, expressive roles are more covert and the role specifications are less identifiable. Therefore, ensuring the emotional well-being of parents probably is more stressful than completing instrumental demands (Sessions, 1987).

When the type of role assignment is not developmentally or age-appropriate, greater destructive parentification occurs. For example, assigning unsupervised family meal preparation to a four year old is developmentally and age inappropriate. The child’s

inability to adequately fulfill this assignment disrupts the normal developmental task stages and may affect mastery of subsequent tasks (Jurkovic, 1997; Olson & Gariti, 1993).

Extent and Duration of Responsibility

As children fulfill their instrumental and/or expressive responsibilities, the degree and duration of parentification is important to consider. To some extent, parentification is a natural, expected part of all parent-child relationships that can contribute to healthy, normal development of children. Occasional and temporary parental reliance on children prevents parents from emotional depletion and allows children to test their potential future roles.

However, when role reversal becomes the typical relationship and behavior pattern, a serious and potentially harmful process occurs (Karpel, 1976). Extensive caregiving by parentified children can lead to emotional and physical depletion (Jurkovic, 1997). Parentified children can be so overburdened that they do not have the time or energy to date, pursue friendships, or participate in age-appropriate activities with peers (Valleau, Bergner, & Horton, 1995).

Causes of Parentification

The nature of parentification is multivariate and many factors are involved; it cannot be explained by a single variable. According to Winton (2003),

[d]ual-worker households, single-parent households, military families, families of chemically dependent persons, families of recent immigrants, families who experience divorce or widowhood, families in which a member is chronically physically or mentally ill, very large families, families in which there is an elderly parent, and families having an incarcerated parent all present greater opportunities for children to become parental or parentified. (p. 61)

However, the social structures of these families only present an opportunity for

parentification to occur; they do not guarantee that it will occur.

Parental Factors

Parental background is an important factor in parentification, especially destructive parentification. Parents' experiences of being parented affect the quality of their parent-child relationships. "Supportive parent-child relationships have been identified as the single most important protective process operating to produce resilient outcomes across several, diverse populations at risk" (Walker & Lee, 1998, p. 528). Parents whose personalities and developmental histories make them needy for support, recognition, and nurturance from others often seek these from their children. "...[T]he operative factor in the histories of many parents of destructively parentified children appears to be the presence of some type of privation, exploitation, or boundary disturbance such as sexual abuse, neglect, pathological parentification, or overprotection" (Jurkovic, 1997, p. 20).

In many parentifying parents, early disruption in attachment to primary caregivers and early emotional deprivation occurred. The primary narcissistic needs for empathy and recognition are thwarted and a core sense of self does not develop. Upon parenthood, these people are more likely to neglect, exploit, or fuse with their children (Jurkovic, 1997). Early exploitation and deprivation also can lead to egotistical parents. Their greatest desire is to have their children fulfill their expectations without regard to their children's preferences and needs. Parental understanding and empathy may be compromised by anxiety caused by serious and prolonged environmental stressors such as single parenting, financial difficulties, and family disabilities or illnesses (Jurkovic, 1998).

Child Factors

Jurkovic (1997) suggested that at least three variables exhibited by children can increase their susceptibility to parentification - temperament, capacity to care, and attachment behavior. Children with very shy or easygoing dispositions are vulnerable to

parentification. Shy children seek refuge and interpersonal gratification from within their family. Parents of temperamentally easy children often overestimate their children's developmental capabilities and expect them to perform age-inappropriate duties. Children who have a developing ability to empathize and care for others often are parentified. The child's pseudomaturity complements the parent's immaturity (Karpel, 1976). As mentioned earlier, disruption of attachment to primary caregivers is a common characteristic of many parentified parents. Destructive parentification "can be seen as the intergenerational transmission of an insecure attachment" (Jurkovic, 1998, p. 241).

Stressors

Stressors that affect the role patterns and structure of the family are likely to increase parentification. They can include the spacing, number, and birth order of the children. The oldest children, especially girls in large families, typically assume the parentified role in the family (Burnett et al., 2006). They provide more family caretaking responsibilities "while males are more likely to exhibit parentified behavior through deviance" (Winton, 2003, p. 56). Older siblings may function as parental surrogates providing supervision, protection, and nurturance for younger siblings. "Older girls are often given many of the household chores while older boys may be withdrawn from school or be expected to help support the family financially after school" (Winton, 2003, p. 114). Parental substance abuse (e.g., drugs and alcohol) also leads to a greater amount of parentification (Godsall et al., 2004; Goglia et al., 1992; Kelley et al., 2007). Children living with single parents are at risk of parentification - particularly those whose parents have divorced. "In addition to sharing responsibility with their parents and siblings for various instrumental tasks, they frequently perform expressive functions, such as serving as their parents' confidants, companions, and even supervisors" (Jurkovic, 1997, p. 29). A healthy marital relationship has been found to be a primary source for strong parental support. However, when there is

marital dysfunction, one or more children may become the scapegoat for the family. Their job is to dissipate or remove the stress from the parental dyad.

Consequences of Parentification

Parentified children, regardless of their age or sex, may experience a variety of cognitive, emotional, and sociofamilial difficulties. As a result of their parentified roles, children frequently develop additional symptoms such as difficulty with self-differentiation, separation problems, school difficulties, depression, anxiety, and shame (DiCaccavo, 2006; Hazen et al., 2005; Nichols & Everett, 1986).

While loss is a normal part of growth and development, it appears to be particularly prominent in parentification. Loss of childhood may be most prevalent for parentified children. However, the disappointment, bitterness, and depression associated with this may not surface until later in life (DiCaccavo, 2006; Jurkovic, 1997; Olson & Gariti, 1993; Stein et al., 1999). Feelings of parental loss, whether physically and/or emotionally, also is common. Pauline Boss (1999) described the emotional or psychological withdrawal or distancing of parents as ambiguous loss. Parents still may be physically present, but they are not emotionally involved with their children. “Of all the losses experienced in personal relationships, ambiguous loss is the most devastating because it remains unclear, indeterminate” (Boss, 1999, pp. 5-6). Loss of trust (trust in parents and others in general) occurs concurrently with the feeling of loss of childhood and parents. The implicit ability of parents to care for children is violated and causes children to mistrust those around them.

Parentified children often feel abandoned or lonely but seldom express this because they are afraid of alienating their parents (DiCaccavo, 2006). However, children may unconsciously act out these feelings through promiscuity, overeating, or substance abuse. They may try to lure others to care for them by using hypochondriac or suicidal gestures

(Jurkovic, 1997). Parentified children also often feel anger and resentment. These feelings typically are suppressed or remain dormant because to express them may hurt or overburden parents and/or threaten the fragile parent-child bond.

The overwhelming stress of handling excessive responsibilities without the necessary knowledge, maturity, or ability may be associated with anxiety, low energy, insecurity, and psychosomatic symptoms (Jurkovic, 1997). Children may feel guilt, shame, worthlessness, and disappointment in their parents because they are unable to fulfill their roles and solve the ongoing family problems. If parents should become ill or die, children may feel responsible; they feel they should have done more to prevent this. Sometimes parentified children may be physically abused because they cannot meet all the needs of their parents. Destructive parentification can lead to incest where parentified children are sexually abused by parents (Herman & Hirschman, 1981; Jurkovic, 1997).

Unhealthy childhood parentification has been associated with narcissistic as well as masochistic personality characteristics in adults (Wells & Jones, 1999). These characteristics occur when the child's "true self" is denied and a "false self" develops to meet the particular needs and expectations of parents (Buchholz & Haynes, 1983; Wells & Jones, 1998; Wells & Jones, 2000). In masochistic parentification, children develop compulsive caregiving because it provides closeness to parents who are emotionally detached, self-absorbed, or inconsistently available. These children may assume the roles of mediator, good listener, organizer, protector, and nurturer of their parents (Jones & Wells, 1996; Wells & Jones, 1999; West & Keller, 1991). In narcissistic parentification, children attempt to meet parental needs by fulfilling their parents' lifelong dreams.

According to Chase et al. (1998), parentified children and adolescents may experience long-term effects such as difficulties in developing a separate and true sense of self in work and adult relationships. "When children are forced prematurely and excessively into

fulfilling parental roles, those children frequently emerge from this experience as adults who are compulsively overfunctioning and caregiving in their relations with others” (Valleau et al., 1995, p. 157). Wells and Miller (2001) concluded that pathological childhood parentification can lead to “chronic overfunctioning, high performance, urgency addiction, and workaholism in parentified adult[s]” (p. 96).

Robinson (1999) stated that parentification in the early years can lead to workaholic children who mature into workaholic adults. A profile of the characteristics of workaholic children shows them to be “the most attentive, dependable, smart, and popular children in school. They follow the rules, always finish their schoolwork in the allotted time, and often are leaders in school government and extracurricular activities” (Robinson, 1999, p. 59). However, while their friends play and are carefree, workaholic children often are serious and contending with adult issues and low self-esteem. Overfunctioning provides them with good feelings about themselves, yet they have difficulties in relinquishing control, trusting, and being intimate (Robinson, 1999). Workaholic children also are known as resilient, transcendent, hurried, responsible, or invulnerable children.

Parentified children may have difficulties forming peer relationships and, therefore, may feel isolated. Often these children complain of not fitting in and view age-related activities and interests as childish. Parentified children may be seen by their peers as being too serious and adult-like. Peer interaction often is exploitive and non-reciprocal. Parentified children may be used by lonely peers for temporary companionship or advice, but peers fail to reciprocate this. Parentified children tolerate this one-sided relationship “because of the social contact and narcissistic gratification they provide” (Jurkovic, 1997, p. 57). Sometimes parents feel threatened if their children take interest in peer activities because this may lessen the amount of support that the children can provide.

To escape responsibilities and home pressures, parentified children may join peer

groups where they may become involved with drug and alcohol abuse or delinquent activities. Parentified teen girls are at risk for early pregnancy. These rebellious behaviors can occur because many parentified parents do not monitor their children's activities. These parentified children signal problems at home and add to the already existing family difficulties. However, sometimes children's self-destructive behavior is a method to pull the family together.

Parentified children exhibit two extreme reactions to leaving home. If they have failed to form an independent identity and are extremely loyal to the family, they do not feel that they can leave the family and live away from home. If they do manage to leave, they may feel extreme shame, guilt, or disloyalty. Alternately, some parentified children attempt to escape the "prison of their childhood" by leaving home at an early age (Jurkovic, Morrell et al., 2001, p. 138).

Similarly, school performance of parentified children also may be dichotomous. If children function to please or meet the needs of their parents, they may be driven students and excel in academics and school activities. In other cases, the duties of parentification may interfere with school performance and attendance causing children to be tired, inattentive, or preoccupied. "[W]hile the overachievers may never be singled out, parentified children who are unable to balance home responsibilities with school endeavors may be recognized and receive assistance" (Chaney, 2002, p. 55).

According to Reeves (1999), parentified children are incapable of reciprocity in give and take relationships. They are most likely to be the givers in relationships as well as assume the roles of consoler, confidant, and/or peacemaker, but they are not capable of fulfilling the roles of mate or companion. "The parentified child usually grows into adulthood psychologically groomed for a life of service to others" (Reeves, 1999, p. 179.) Sessions (1987) found that parentified children who carried extreme amounts of adult

responsibilities were more likely to choose a career from the helping professions, including those in the psychotherapeutic field. Jurkovic (1997) noted that therapists who had been destructively parentified at some point in their lives exhibited various professional, ethical, and personal problems in their therapist-client relationships. These difficulties ranged from high degrees of occupational burnout to boundary distortions (Jurkovic, 1997; Ward, 1999).

As parentified children reach adulthood, problems from their earlier years may create additional difficulties. Chronic worrying, anxiety, feeling overwhelmed, addictions (e.g., food, work, alcohol), inability to say no without guilt, inadequate self-care, orientation to pleasing others, depression, resentment, and bitterness are some of the liabilities and at-risk characteristics of adults who were parentified as children (Chase, 2001). Feelings of anger, sadness, loneliness, and fear of others' reactions; difficulty with decisions, leaving home, relationships, and parenting; and being overly compliant, controlling, and responsible are a few of the symptoms, behaviors, and issues that may be attributed to adults with histories of childhood parentification. These characteristics often become sources of pain, confusion, and problems for adults (Chase, 2001). For example, adults, who were parentified children, often will seek codependent relationships with other needy, addicted, or narcissistic partners in hopes of changing their partner's behavior (Jurkovic, 1997; Jurkovic, 1998).

Parentification and Divorce

Recent research on divorce and parentification has shown that divorce does not have to lead to destructive parentification. Schimming (2001) noted that there were "few relationships between parentification and adolescents' psychosocial functioning, aside from the ability of adolescents from DSPFs [divorced single-parent families] to manage conflict and, to some extent, provide emotional support and advice in relationships" (p.iii).

In 2001, Jurkovic, Thirkield et al. reported in their research on adult children of divorce that no destructive parentification was noted in almost 50% of the participants from divorced families. They stated that with an appropriate balance of give-and-take in the family, even extensive caretaking responsibilities can lead to beneficial effects of divorce.

Current Research on Children as Caregivers to Ill Parents

Children who are parentified also can be considered young caregivers. If women continue to give birth at older ages and the incidence of chronic diseases continues to rise, more children will become young caregivers by necessity. While there is no precise information on the prevalence of early caregiving in the United States, it is estimated that more than 1.3 million children between the ages of 8 – 18 are caregivers, with 31% between the ages of 8 to 11, 38% between ages 12 to 15, and 31% between ages 16 to 18. Child caregivers are evenly matched by sex (females 51%, males 49%) and live in single-parent households with lower incomes. Approximately 72% of child caregivers are caring for a parent or grandparent with 28% of them caring for their mother and 11% helping with a sibling (National Alliance for Caregiving, 2005).

Most of the research on young caregivers has been conducted in the United Kingdom in the 1990s and suggests that “individuals under 18 years old may be in a primary caregiving situation for a parent or older relative at a much higher rate than people imagine” (Shifren & Kachorek, 2003, p.339). However, there is little information or research being conducted in the United States on caregiving experiences of children and youth or “the long-term effects on the young caregivers’ adult development” (Shifren & Kachorek, 2003, p. 338).

Summary

Chronic illness differs from terminal or acute illness in that it is considered to be a long-term or permanent condition. More than 133 million people are living with chronic

diseases (Partnership for Solutions, 2004) and many of these people are in their child-rearing stage of life. This statistic indicates that large numbers of children are living with chronically ill parents during their developmental years.

According to family systems theory, families are systems of interdependent, interacting individuals. They are made up of smaller units called subsystems which can include marital, parental, and sibling subsystems that have reciprocal influences on each other (Bradford & Barber, 2005). From a family systems perspective, when a mother develops a chronic illness, other subsystems also will be affected. Recent research has indicated that chronic illness of a family member affects the entire family system (Eriksson & Svedlund, 2006; Sholevar & Perkel, 1990; Steele, Forehand et al., 1997). For example, maternal chronic illness has been associated with depression, anxiety, and a sense of loss. Often, parenting becomes more difficult when mothers are restricted in their abilities to perform certain parenting tasks, are no longer available to participate in family/school functions, and need to rely on their children for help. Children's adjustment to their mother's illness depends on the child's age and developmental abilities. However, if the mother is depressed, there also is a greater risk of the child becoming depressed, and if the mother has chronic pain, there may be an increase in somatic complaints from the child (Hendren, 1990; Mikail & Baeyer, 1990).

The central focus of family development theory is on families as interacting groups of people. Each family member has specific roles. When one member of the family is unable to fulfill his/her role, other members may try to fill the vacancy. Parentification occurs when children attempt to fill the role of a parent. It becomes destructive when children perform extensive caretaking duties that are not age-appropriate, their activities are not acknowledged or reciprocated, and their duties violate generational boundaries.

The effect and extent of parentification in maternal chronic physical illness may be

moderated by the amount and type of perceived social support received by both the mother and child. Social support and social networks may provide a buffer against stress, anxiety, and depression associated with illness (Fyrand et al., 1997).

Studies on chronic illness have been conducted on the entire family, the chronically ill individual (particularly children), and the spouses of the ill member. There is a limited amount of research on the children of parents with chronic illness. Specifically, rheumatoid arthritis and many of its aspects have been studied extensively. Yet, little research has been done on mothers with rheumatoid arthritis and the effects of this illness on her children. In addition, fibromyalgia remains a complex and controversial condition that is poorly understood. The medical community and researchers cannot agree on its etiology, diagnosis, treatment or even whether it is a true disease, and no research has been conducted on mothers with fibromyalgia and how this illness may affect their children.

The present study was designed to focus on parental illness and the effects on children. As indicated above, a parent's chronic illness, as with any other family stressor, affects not only the parent but the family system. The responses to it may be multiple and diverse. One potential response to the parent's illness is that of a child's parentification. This study, building on related research, examined some of the many factors that may affect the likelihood of its occurrence. By doing so, the researcher sought to determine the extent and nature of parentification in adolescents with mothers who have fibromyalgia and rheumatoid arthritis in order to better understand the need for developing appropriate preventive and intervention strategies.

Chapter 3

METHOD

The primary purpose of this study was to explore the relationship of a mother's chronic physical illness (fibromyalgia [FM] and/or rheumatoid arthritis [RA]) to the parentification of her adolescent child. This chapter provides a detailed description of how this study was conducted. After reviewing participant demographics, the sample selection criteria and strategies for recruitment, measures for assessing the identified variables, and procedures for data collection, processing, and analysis are described. The chapter concludes with a description of the aspects of the study that limit the interpretation of the study findings.

Study Sample

Population Criteria

The study sample was restricted to mothers ranging in age from 25-57 years who had been diagnosed with FM and/or RA by a practicing rheumatologist or physician, and who had at least one pre-adolescent or early to mid-adolescent child (ages 11-17) living at home. The effects of these diseases, however, could not be so severe that participants would be unable to complete written questionnaires. Also, to be able to complete the written assessments and communicate with the researcher, mothers and children needed to be reasonably fluent in English. Various family structures, including two-parent, single-parent, step- and blended families were included in this sample. If there were more than one adolescent child in the family, the oldest one within the required age range who had not been identified as requiring special education services was asked to participate in this study. To participate in this study, completed surveys from both the mother and child needed to be returned.

Sample Characteristics

Six hundred packets (300 mother/child sets) were mailed to interested respondents across the country. Of these, 436 (218 mother/child sets), or 72.7% of the packets, were returned and 200 mother/child sets, or 91.7% of completed surveys, were used in the study. Eighteen (8.3%) of the returned surveys were disqualified or not used because five of the child respondents were older than 17 years, one child respondent was not living at home, one child respondent did not answer at least 80% of the items on the parentification survey, six children and two mothers did not return their surveys, two mothers completed their child's surveys, and one mother did not return a consent form.

The resulting sample included 200 mothers with a mean age of 42.3 years ($SD = 5.94$), ranging from 29 to 57 years old. Six percent of the mothers reported that they had RA ($n = 12$), 79.5% ($n = 159$) reported FM, and 14.5% ($n = 29$) reported having both illnesses. The majority (87%, $n = 174$) of the 200 mothers who participated in the study stated that they were Anglo/Caucasian; the remaining 26 participants indicated that they were Hispanic ($n = 8$), American Indian ($n = 9$), or African-American ($n = 7$). The "other" category comprised the responses of 2 mothers who described themselves as multi-ethnic or of middle-eastern ethnicity. The majority of the mothers were living with their spouse or partner (75.5%, $n = 151$). Those who responded as single, never married, separated, divorced or widowed accounted for 24.5% ($n = 49$) of participants. Forty-three mothers (21.5%) indicated that they had no college education, 126 (63%) reported some college or a Bachelor's degree, and 31 (15.5%) had pursued some post-graduate courses or received a Master's or Doctoral degree. The majority of participating mothers (58.5%, $n = 117$) stated that they were not working outside the home and described themselves as unemployed, retired, homemakers, or disabled. The remainder of participating mothers (41.5%, $n = 83$) reported being employed full-time (27.5%, $n = 55$) or part-time (14%, $n =$

28). The average household size reported was 4 people ($M = 3.79$, $SD = 1.17$), with the age range of 1-18 years for children living at home and the age range of 19-79 years for those 19 years and older at home.

Table 1

Distribution of Age and Sex of Children in Study

Age	Male	Female	Total
11 to 14 year olds			
11	10	13	23
12	10	8	18
13	9	12	21
14	19	14	33
Total	48	47	95
15 to 17 year olds			
15	13	15	28
16	14	27	41
17	27	9	36
Total	54	51	105
Grand Total	102	98	200

Two hundred children participated in this study. As seen in Table 1, sex was approximately equally divided with 51% ($n = 102$) males and 49% ($n = 98$) females. The children's ages ranged from 11-17 years ($M = 14.5$, $SD = 1.97$), with a mean age of 14.62

($SD = 2.02$) years for males and 14.30 ($SD = 1.92$) years for females. For children aged 11-14 years ($n = 95$), the mean age of males was 12.77 years ($SD = 1.19$) and the mean age for females was 12.57 years ($SD = 1.19$). The younger age group (11-14 years) consisted of 48 (50.5%) males and 47 (49.5%) females. For children aged 15-17 years ($n = 105$), the mean age of males was 16.26 years ($SD = .83$) and the mean age for females was 15.88 years ($SD = .68$). This older age group (15-17 years) consisted of 54 (51.4%) males and 51 (48.6%) females. The majority (87.5%, $n = 175$) of the children in the sample indicated their ethnicity as Anglo/Caucasian; 5.5% ($n = 11$) reported that they were Hispanic, Mexican American, or Latina; 3% ($n = 6$) stated that they were African-American; 1.5% ($n = 3$) responded that they were Native American Indian; and 1% ($n = 2$) answered as being Asian or Pacific Islanders. Under the “other” category, two children (1%) indicated that they were multi-ethnic. One child did not answer this question.

As shown in Table 2, the children were enrolled in grades 4 - 12 and two reported taking some college classes. The largest number of children ($n = 41$, 20.6%) attended grade 11. Most of these children ($n = 168$, 84%) were not employed. However, of the 32 employed children, 31% worked in the food service industry and 31% were office workers or sales clerks. The mean number of hours of work per week for the 32 (16%) employed children was 12.22 hours ($Mdn = 10.50$, $SD = 6.73$). The mean number of hours of free time reported by the youths ($N = 183$) was 12.07 ($Mdn = 8.0$, $SD = 13.27$).

Recruitment Strategies

After approval was received from the University of New Mexico’s Human Subjects Institutional Review Board (UNM IRB) and a local hospital review board to conduct this research study, rheumatologists in local private practices were contacted. A list of practicing rheumatologists, who also were members of the American College of Rheumatology (ACR), was obtained from the ACR website member’s directory. This site

Table 2

Distribution of Children's Grade in School

Age	School Grade										Total	
	4	5	6	7	8	9	10	11	12	13 ^a		
11	1	8	13	1								23
12			3	15								18
13				3	16	2						21
14					12	20	1					33
15					1	6	19	1	1			28
16							12	28	1			41
17								12	21	2		35 ^b
Total	1	8	16	19	29	28	32	41	23	2		199 ^b

^aTwo high school seniors were taking college courses. ^bOne 17-year-old male had dropped out of school.

also provided physicians' contact information. Additional names of rheumatologists were obtained from the city's telephone directory.

Working with rheumatologists (as opposed to working with other types of physicians) was preferred because rheumatologists are specifically trained to diagnose patients with FM and RA using explicit criteria developed by the ACR. FM is not considered to be a specific disease; it is believed to be a syndrome or a collection of symptoms that include widespread body pain, hypersensitivity to palpitation of certain specific body points (tender points), fatigue, disturbed sleep, memory and concentration problems, and

depression and anxiety (Dailey, Bishop, Russell, & Fletcher, 1990; Hughes, 2006; Levine & Reichling, 2005). RA is considered to be a particular form of arthritis with unique symptoms, such as fatigue, occasional fever, malaise and tender, swollen, red, warm joints. Since both FM and RA have their own set of symptoms, it was important that participants in the study have official diagnoses of these illnesses. (As noted in the introductory chapter, these illnesses were chosen because although they are debilitating, they are not life threatening. Also, it was believed that the cyclic nature of FM and RA would allow the researcher to specifically investigate the amount of parentification that takes place during flare ups and remission.)

With permission from local rheumatologists, the author left flyers (see Appendix A) at the front desk of patients' waiting rooms. These provided a brief description of the study and furnished researcher contact information to potential voluntary participants. Letters explaining the study and accompanied by a stamped post card (see Appendices B and C) were attached to the flyers. If the contactees were interested in participating in this study, they were asked to return the enclosed post card that asked for their name, address, telephone number, best times to call, age of oldest child, and their willingness to have their child participate. Potential participants who returned post cards were contacted by telephone to discuss the purpose of the study, voluntary participation, and confidentiality (see Appendix D). If these women verbally agreed to participate, the researcher explained that consent/assent forms inviting their participation and the participation of their oldest child living at home would be included in their respective packets. (See Appendices E and F.) These consent forms described the study and assured them that participation was voluntary and individual responses would remain confidential so that no respondents could be identified. It was noted that risks were considered to be minimal and that potentially sensitive issues were few. However, in responding to questions, if painful memories or

concerns were raised, a list of counseling resources was offered. The author also explained that there would be no penalty for not participating and this would not affect the medical care/treatments they currently were receiving.

Since response rates were extremely low, an additional letter mailing and one reminder mailing were conducted at two- to three- week intervals. However, participation rates continued to remain exceedingly low; only two of the 150 desired mother/child pairs were recruited in 12 months. With the approval of the researcher's dissertation committee and the UNM IRB, the researcher implemented several modifications to the recruitment procedure. These modifications included: decreasing the required sample size from 150 mother/child sets to 75 mother/child sets, eliminating an originally proposed lengthy medical questionnaire (the Arthritis Impact Measurement Scales 2) to enable completion of surveys by the mother in 30 minutes or less, increasing the age range of youth participants from 11-16 years to 11-17 years, working with the local chapter of the Arthritis Foundation, contacting the Arthritis Foundation chapters nationwide (after receiving the Arthritis Foundation's approval), and contacting rheumatologists throughout the state. However, after an additional three months, only four of the required 75 mother/child participants had been recruited.

Initially, RA was the only illness to be studied. In an attempt to increase the number of participants, the Chief of Rheumatology at a local hospital and a nurse practitioner at the local Arthritis Center recommended that FM be added to the study as a second source of chronic physical illness. The researcher received approval from her dissertation committee and the UNM IRB to add this illness to the study. Approval also was given to contact major arthritis and FM websites, electronic mailing lists, and support groups located via the internet. Administrators of the following services were contacted and approval was provided to place ads and/or invitations on these sites: Co-Cure (www.co-cure.org), the

National Fibromyalgia Association online newsletter (www.fmaware.org), the National Fibromyalgia Partnership's (www.fmpartnership.org) quarterly journal, Fibromyalgia Frontiers, and the Las Vegas FMS/CFS Support Group (<http://communitylink.reviewjournal.com/lvrj/lvfcfs>). Several list serves (FIBROM-L [www.fmscommunity.org], Fibrohugs [www.fibrohugs.com], and Reaching Out [www.reaching-out.info]) also provided information about this study to their members. The number of responses was overwhelming. In six months, 296 sets of surveys were mailed to potential participants.

Variables and Measures

Two questionnaires were developed by the researcher, one each for both the mother and the child. The child's questionnaire contained 19 items and included questions on the following: background characteristics, perceived impact of the illness, the parent-child relationship, changes in child's life due to the mother's illness, and sources of support. The mother's questionnaire contained 34 items and addressed the same content areas as the child's questionnaire. A section on the characteristics of the mother's illness was added to her questionnaire.

Prior to the distribution of the researcher-developed questionnaires, a pilot study was conducted to assess the appropriateness and intelligibility of the wording and format of these instruments for the target populations. Twenty youth reviewed their questionnaire. They suggested the following: "[b]urdened is not a word that a 13-year-old uses a lot. Could you use another word?" The researcher substituted "bothered". Use "good" and "bad" instead of "positive" and "negative". One of the questions stated, "It is common for people of all ages to experience stress. What stresses have you experienced during the past year?" A child asked for examples of stress to be included in the question. As a result, these minor suggested editing changes were made.

Ten mothers reviewed the parent's questionnaire. One of the questions asked that the answer be filled in when it really needed to state, "Please circle the answer". Another mother suggested changing the statement, "Please list the typical responsibilities and duties the child in this study at home performs in the family" to "Are there any family responsibilities and duties that the child in this study usually performs?" Both of these changes were made. It also was determined that approximately 30 minutes would be needed to complete the mother's and child's questionnaires.

Demographic Variables

Mother

To obtain demographic data, the self-report form developed by the researcher was completed by the mother. The form requested general background information such as age, ethnicity/race, marital status, educational level, employment status, and number, age, sex, and relationship to the mother of all people residing in the household. (See Appendix G.)

Child

The targeted child was asked to complete the brief questionnaire developed by the researcher that provided information on age, sex, ethnicity/race, educational level, amount and type of employment, and hours per week in leisure activities. (See Appendix H.)

Characteristics of Mother's Illness

Medical History - Mother

The mother's self-report questionnaire included a section on her medical history pertaining to FM and/or RA such as type, frequency, and severity of symptoms; number and length of flare ups; onset and length of diagnosis; and course of treatment during flare ups and remissions. (See Appendix G.)

Perceived Impact on Family

The researcher-developed questionnaire for the mother also assessed the mother's perceptions of the influence (both positive and negative) of her illness on herself and her family, including the amount of burden experienced by herself and the targeted child, any perceived changes in the child's behavior at home and school, and the perceived quality of the parent-child relationship. (See Appendix G.)

The researcher-developed questionnaire for the child also asked him/her to describe perceived positive and negative aspects of the mother's illness and any changes that may have occurred during the past year in his/her school activities (e.g., grades, attendance, extracurricular activities) and leisure activities (e.g., hobbies, time with friends, activities outside of school). The youth also was asked to assess the quality of the relationship with his/her mother and the degree of burden felt from the mother's illness. (See Appendix H.)

Parentification

Mother

To assess for possible past (intergenerational) parentification of the mother, a question was included in the researcher-developed questionnaire for the mother pertaining to types of additional responsibilities and duties the mother may have performed for her family when a parent was ill during her youth. (See Appendix G.)

Child

The Parentification Questionnaire - Youth (PQ-Y), developed by Godsall and Jurkovic (1995), was used to assess the extent of the target child's parentification. This instrument is a later version of the authors' Parentification Questionnaire-Adult (PQ-A). Verb tenses were changed from past to present tense and the vocabulary lowered to a third-grade reading level. The number of true-false items was reduced from 42 to 20 and the true-false responses were changed to yes-no answers. Of these 20 questions, 15 of them indicate

parentification if answered “yes”. The remaining 5 questions indicate parentification if answered “no”.

The PQ-Y describes current life situations in the youth’s family or what life was like while they were living at home (Godsall et al., 2004). Examples of statements are: “I often have to do other family members’ chores”, “I often feel like a referee in my family”, and “It seems that people in my family bring me their problems”. This measure has been found to be internally consistent (coefficient alpha = .75 - .83). According to Godsall (1995), it is appropriate to use with heterogeneous groups of pre-adolescents and adolescents ages 10-17. It is estimated to take approximately 10-15 minutes to complete (G. J. Jurkovic, personal communication, May 27, 2003).

Child’s Family Responsibilities and Duties

Types of responsibilities and duties performed by the child during flare ups and remissions of the mother’s illness were assessed with items included in both the mother and child’s questionnaires. (See Appendices G and H.)

Other Relevant Personal-Social Variables

Perceived availability and satisfaction with sources of support was assessed with items included in both the mother and child’s researcher-developed questionnaires. (See Appendices G and H.)

Data Collection Procedures

After receiving approval from the mothers who volunteered to participate, the researcher mailed survey packets to them and their participating children. The mother’s packet contained a set of instructions (see Appendix I), the researcher-developed questionnaire, two informed consent forms for her participation (both to be signed and one to be returned to the researcher), two parent/legal guardian forms (see Appendix J) providing permission for her child to participate in the study (both to be signed and one to

be returned to the researcher), and a request for notification of results form (see Appendix K). The youth's packet contained a set of instructions (see Appendix L), the researcher-developed questionnaire, the Parentification Questionnaire – Youth (PQ-Y), three Assent forms (all to be signed, with one given to the mother, one kept by the youth, and one returned with the surveys) and a request for notification of results form. Stamped return envelopes were included in both the mother's and child's packets.

Data Processing and Analysis Procedures

Data Processing

All questionnaires were coded to conceal participants' identities. Each mother/child team was assigned the same number with one additional letter - "A" for mother and "C" for child. These individual codes were used on all items throughout the study to provide confidentiality and to organize and interpret the data. All returned materials were filed and stored in a locked file at the researcher's home.

Prior to analysis, participants' responses to the questionnaire items were coded. Variables were assigned specific numbers or abbreviated names as identifiers. Attributes of variables (e.g., sex - male, female) were represented by numerical codes. Variable identifiers and codes were listed in a codebook. The resulting coded data were entered directly into a computer. Statistical analyses were completed by using the data analysis computer program Statistical Package for Social Sciences (SPSS) 11.0 for Macintosh. Prior to analysis, the data were checked for missing data and outliers. (Scores that were three standard deviations above or below the mean were considered as outliers.) No outliers were found. Cases with missing data were rechecked. Errors were located and recoded in the SPSS spreadsheet.

The mother and child questionnaires contained thirty open-ended items. Content analysis was conducted on responses to those items related to the specific research

questions in this study. Following the recording of all responses to each item, a reduced set of categories was developed for each question that represented a manageable number of distinct themes or ideas for which frequency distributions were singly obtained or in some cases, in combination. Following a review by the Chair of the Dissertation Committee and an ensuing discussion, these categories were finalized for subsequent analyses.

In coding the PQ-Y, it was found that 43 youths did not answer all 20 questions. Jurkovic (co-author of the PQ-Y) was contacted to determine how to treat the missing data (G. J. Jurkovic, personal communication, June 30, 2006). He advised the researcher to substitute the mean score for each question so that the overall mean for each question would be maintained. He also suggested that if less than 80% of the items on the questionnaire were answered, it should be disqualified because of validity issues.

Data Analysis

Initially, descriptive statistics were obtained for all coded responses to the parent and child questionnaires for the total sample, separately by the mother's illness, and where appropriate, by the child's sex. For each instrument, frequencies, percentages, and, where appropriate, measures of central tendency (mean, median, mode), and measures of variability (standard deviation and range) were calculated for every variable assessed. In addition to providing detailed descriptive information on the sample, such information was necessary to determine the appropriateness of the specific measures to be used in the subsequent analyses.

Prior to performing analyses to address the posed research questions and to better understand the meaning of the specific measure, correlations were obtained between all measures within and across variables. Scatter plots also were drawn to assess potential relationships. For instance, correlations were obtained among the demographic measures as well as between PQ-Y scores and all mother and child variables. This helped to

determine which measures to use in the cross-domain analyses. Correlation, analysis of variance (ANOVA), and regression analyses were considered and if appropriate, conducted to further investigate the research questions.

Limitations of the Study

Due to the exploratory nature of this study, limitations were likely to occur because of conditions noted in the following paragraphs:

Obtaining an adequate sample size was an arduous process. The researcher believes that many mothers with RA may not have felt and/or may not have wanted to think that their illness affected their children, and consequently, they did not see a need to join the study. Due to medical advances, RA flare ups can be brought under control within 1-2 days given changes in or additional medications. Therefore, some mothers feel that they are able to lead fairly normal lives without interruptions and their children are not exposed to RA as a lengthy illness. Thus, they may not view themselves as appropriate for this type of study.

However, this apparently is not as true for mothers with FM. Many mothers with this illness said they wanted to participate because they were concerned about how their illness was affecting their children and family. Yet, many of them expressed concerns about participating and they directly contacted the researcher to ask how and where the results of this study were going to be used, whether the researcher was knowledgeable about FM, and whether the researcher had FM. They expressed concern about sharing information because in the past, their illness credibility had been compromised. They revealed that many in the medical community do not believe that FM is a physical illness and as patients, they have been ignored or patronized.

Sample selection and size also was restricted by the choice of the diseases (FM and RA) and the number of mothers with RA and/or FM who have children aged 11-17 living

with them. Since the majority of participants responded to invitations/ads placed on the internet, the representativeness of the study sample was partially limited to those who owned computers and/or had the necessary skills to access the websites. Also, mothers and children volunteered to take part in this study, thereby creating a non-random, self-selected sample.

Consequently, sample bias was present since participants may not be typical or representative of the population of physically chronically ill mothers or mothers with RA or FM. This study focused exclusively on only two rheumatic diseases (RA and FM) and any significant results are applicable only to people with these conditions who are similar in other characteristics to the study participants. Since participants were sought from rheumatology clinics and through internet FM and RA associations and support groups, they may represent people who are more severely affected by these illnesses (Barlow, 1998; DeVellis, 1995). People with less severe cases of FM or RA might have responded differently to the measures. Furthermore, they may have entered the study during a flare up of disease activity, but then improved before data collection was completed. This fluctuation in disease can bias the responses at any given time (Young, 1992). Also, significant differences in amount and type of medical care have been shown for those of minority and low-income status. The majority of mothers in the study were Caucasian and had attended college. Therefore, generalizability of the findings is limited to the research participants or people highly similar to the study sample.

Responses to self-report questionnaires may have been limited in reliability and validity because they were dependent on the participant's honesty, comprehension or interpretation of the questions, and desire to answer as s/he believed the researcher desired. Also, self-report measures generally assess only the individual's perceptions, although such perceptions may influence behavior. The retrospective nature of self-report also

assumes that people remember past events accurately, but recall bias may have influenced these reports (Katz, 1995; Sakalys, 1997; Zautra et al., 1997).

Measures of symptoms tend to ask respondents about symptoms they have experienced during a relatively brief time period (DeVellis, 1995). In this study, the mother's questionnaire asked participants to recall items that occurred during the past month. Unless FM and/or RA flare ups occurred during the four weeks prior to completing this measure, the responses may not have accurately captured what occurred during one of these episodes. Furthermore, due to the "fibro fog" that is characteristic of FM, these mothers may have had problems accurately recalling information.

There also may have been a threat to an instrument's internal validity from external changes that occurred. For example, during the past year, there has been considerable attention given to FM in the healthcare arena. Media attention to this illness has increased dramatically with the recent FDA approval of the first prescription drug to treat FM. It is possible that the news media may have presented information to the public that influenced participants' answers. In addition, contamination also may be an issue. In the general instructions, participants were asked not to discuss their responses until after they returned the questionnaires. However, they may not have complied with this request since some attended common physicians, support groups, and internet sites and they did not complete the materials at the same time. Also, although the parent and child were asked not to discuss their answers before mailing back their questionnaires, there still may have been a possible influence of the parent on the child's responses. For example, children's responses may have been affected by their fear of parents knowing/seeing their answers.

In addition, by using a standard questionnaire some of the study variables may not have been accurately measured. For example, the PQ-Y is designed for use with two-parent families. Questions #14 in the PQ-Y states, "My parents are very helpful to me when I

have a problem.” Questions #16 states, “My parents seem to disagree about everything.” This study was not restricted to only that family type. Therefore, using this instrument with respondents in other family structures may have been inappropriate and may have yielded inaccurate results. Because of this concern, the researcher asked for and received permission from Jurkovic, co-author of the PQ-Y, to add the word “parent” to questions #14 and #16 (personal communication, November 3, 2003).

Accurate responses on the PQ-Y also may have been affected by the respondent’s emotions such as unconscious anger toward parents or feelings of guilt or loyalty. While the PQ-Y identified respondents who perceived themselves as parentified, it is difficult to conclude that these people had actually experienced parentification (Davidson, 1986). Also, as Goglia (1982) noted, responses may have been affected if youth respondents were unaware of their role distortions; they may “under-report the parentification patterns which exist in their families” (p. 50).

Limitations of this study notwithstanding, it is believed that the findings of this research study have implications for intervention, prevention, and future research. It clearly is a topic that needed to be explored in order to expand the knowledge base on parentification so as to facilitate development of prevention and intervention strategies to further support children and their families.

Chapter 4

RESULTS

The purpose of this chapter is to provide the reader with a description of the study findings. Descriptive statistics for the various study measures are presented first, initially providing information on the mothers' and youths' medical histories. These are followed by descriptions of the mothers' and youths' reported feelings of burden by the mothers' illness, perceived positive and negative effects of the illness on their relationship, satisfaction with the support each received, reported family duties and responsibilities of the child, the closeness of the mother-child relationship, and reported changes in the child's life due to the mother's illness. This is followed by a description of the youths' PQ-Y (parentification) scores. Within the discussion of each measure, findings from correlational analyses conducted within domains are presented. The remainder of the chapter presents the results of the analyses for each of the posed research questions addressing the relationship of selected variables to the youths' parentification scores. The chapter concludes with a summary of the findings.

Descriptive Statistics for Study Variables

Medical History

Mother

Rheumatoid arthritis (RA) was reported by 41 mothers. The mean age of onset noted was 30.39 years ($Mdn = 35.0$, $SD = 11.79$), with the reported age ranging between 3 to 48 years. The mean age given for when they were diagnosed was 34.85 years ($Mdn = 36.0$, $SD = 11.21$), with the age ranging between 4 to 51 years. The mean length of illness reported was 12.44 years ($SD = 11.50$). Rheumatologists and/or primary care physicians reportedly made the diagnosis of RA in 92.7% of the cases ($n = 38$).

Fibromyalgia (FM) was indicated by 188 mothers, with 29.62 as the mean age of onset for the 186 mothers who responded. Symptoms of FM were stated to have first occurred between the ages of 3-51 years ($Mdn = 30.0$, $SD = 9.75$, $N = 187$). The reported mean age of FM diagnosis was 36.72 years ($Mdn = 36.0$, $SD = 6.53$), with the age ranging between 20 to 53 years. The mean length of illness reported was 12.68 years ($SD = 9.26$). In 87.8% of the cases ($n = 165$), the diagnosis of FM was made by a rheumatologist and/or the mother's primary care physician.

On a scale of 1-5, the mean rating reported for severity of symptoms was 3.70. Sixty-one percent of the mothers ($n = 122$) rated the symptoms as very to extremely severe. The majority (79.5%, $n = 159$) reported experiencing symptoms everyday, with only 1% ($n = 2$) reporting no symptoms during the past month. RA and FM often are described as including flare ups and 74.4% of the 199 mothers ($n = 148$) reported this in the present study. At the time of completion of the questionnaire, the 140 mothers who responded to the question regarding flare ups, 60% ($n = 84$) stated that they were experiencing flare ups and an additional 31.4% ($n = 44$) reported they had undergone flare ups within the current or past month. The correlation between the length of the longest illness experienced and the severity of symptoms reported was not significant ($r = -.05$).

Slightly more than one-third (34.2%, $n = 68$) of the 199 mothers who responded claimed that during their childhood, their parent(s) had been chronically ill or unable to do things. Of these respondents, 82.4% ($n = 56$) stated that their duties changed during such times.

Child

When asked if they had any health problems, 57.5% of the children ($n = 115$) responded that they did not. However, of the 85 children (42.5%) who reported health problems, most were female or between the ages of 11-14. Twenty-four (28.2%) were found in each of the following categories: males aged 11-14 years, females aged 11-14, and females aged

15-17. The lowest reported incidence of illness was found in males aged 15-17 years ($n = 13$, 15.3%). The three most frequent health problems reported were asthma ($n = 27$), allergies ($n = 17$), and ADD/ADHD ($n = 14$). Other health problems noted by the children were anxiety, back problems, bipolar disorder, depression, diabetes, dyslexia, FM, gastroesophageal reflux disease, headaches/migraines, heart problems, irritable bowel syndrome, knee problems, obsessive/compulsive disease, overweight, pain, panic attacks, plantar fasciitis, and Raynaud's syndrome.

Attitudes about Mother's Illness

Mother

On the average, mothers gave a rating of 3.99 ($SD = .84$) on a scale from 1 to 5 when responding to how burdened they felt by their illness. As can be seen in Table 3, 75.4% of the 199 mothers who responded ($n = 150$) said that they were very or extremely burdened, with only one person stating that she did not feel burdened by her illness. In addition, 96% of 198 mothers ($n=190$) reported that during the past year, they had experienced stresses due to RA and/or FM. Approximately 44% of the mothers (43.5%, $n = 87$) said that they believed their child was somewhat burdened by their illness and another 27% ($n = 54$) stated that they felt their child was very or extremely burdened; however, 29.5% ($n = 59$) reported that their child was only slightly or not at all burdened by their illness. The vast majority of the mothers reported that their illness had affected their relationship with their child, with 142 of the 196 mothers who responded (72.4%) stating that there were positive effects and 171 of the 199 responding mothers (85.9%) reporting that there were negative effects.

Table 3

How Burdened by Mother's Illness the Mother and Child Reported Feeling

Level of Burden	How burdened mother feels (%)		How burdened child feels (%)				
	She is <i>N</i> = 199	Child is 200	All 198	Males 102	Females 96	11-14 94	15-17 104
Not at all	0.5	7.5	11.1	15.7	6.3	11.7	10.6
Slightly	4.0	22.0	15.2	14.7	15.6	14.9	15.4
Somewhat	20.1	43.5	34.8	40.2	29.2	36.2	33.7
Very	46.2	18.5	28.3	21.6	35.4	30.9	26.0
Extremely	29.1	8.5	10.6	7.8	13.5	6.4	14.4

Child

When asked how bothered they felt by their mothers' illness, the children gave an average rating of 3.12 ($SD = 1.14$) on a scale of 1 to 5. As also can be seen in Table 3, of the 198 children who responded, 38.9% ($n = 77$) described themselves as very to extremely burdened, 50% ($n = 99$) as only slightly to somewhat burdened, and 11.1% ($n = 22$) said that they were not burdened at all. Nearly thirty percent (29.4%, $n = 30$) of the 102 males and almost half (49%, $n = 47$) of the 96 females reported being very or extremely burdened. Thirty-seven percent (37.2%, $n = 35$) of the 94 children aged 11-14 stated that they were very or extremely burdened by their mother's illness. For the 104 children aged 15-17 years, 40.4% of the youth ($n = 42$) described themselves as being very or extremely burdened.

Additional analyses were conducted to assess the relationship between how burdened the mother felt by her illness and how burdened she felt her child was by her illness. A statistically significant correlation, $r(197) = .42$, $p < .0005$ (two-tailed), was obtained,

suggesting that mothers who felt more burdened by their illness were more likely to believe that their child felt burdened by the mother's illness. Further analyses were conducted to assess whether this relationship differed significantly by the child's sex or age group (i.e., 11-14 years and 15-17 years). Correlations were statistically significant for both sons and daughters (for males $r(99) = .40, p < .0005$ and for females $r(96) = .41, p < .0005$ (two-tailed)) and for both children 11-14 years old, $r(92) = .40, p < .0005$ (two-tailed), and those 15-17 years old, $r(103) = .46, p < .0005$ (two-tailed). These analyses suggest that mothers in the study who felt burdened by their illness were more likely to believe that the target child was burdened by their illness regardless of that child's sex or age. In addition, a significant correlation was obtained between how burdened both the mother and target child felt by her illness, $r(195) = .26, p < .0005$ (two-tailed), indicating that when mothers felt burdened by their illness, their children also felt burdened, and the more mothers felt burdened, the more their children felt burdened.

Table 4 presents the percentage of children who reported positive and negative effects of their mother's illness both for the total group and separately by sex and age group. The majority of the 199 youths (65.8%, $n = 131$) reported that their mother's illness had affected them in negative ways; 40.7% ($n = 81$) of them noted it had affected them in positive ways. As can be seen, although the majority of both boys and girls stated that their mothers' illness had affected them negatively, a significantly higher percentage of girls than boys did so (75.3% vs. 56.9%). Although only 29.4% ($n = 30$) of the 102 boys responded that their mother's illness had affected them in positive ways, more than half (52.6%, $n = 51$) of the 97 responding girls reported that it did. As can be seen when comparing the children's responses by age group, the percentages did not differ significantly, with younger and older youth reporting 37.2% to 43.8% positive effects and a significantly higher percentage (66%) in both age groups reporting negative effects.

Three fourths (75.5%) of the children ($n = 151$) responded that they had experienced stress during the past year due to their mother's illness.

Table 4

Perceived Positive and Negative Effects of Mother's Illness on Child

Effectuated	% of children affected				
	All <i>N</i> = 199	Males 102	Females 97	11-14 94	15-17 105
Positively					
Yes	40.7	29.4	52.6	37.2	43.8
No	59.3	70.6	47.4	62.8	56.2
Negatively					
Yes	65.8	56.9	75.3	66.0	65.7
No	34.2	43.1	24.7	34.0	34.3

Level of Support

Mother

Of the 167 mothers who answered the question regarding support from their husband/partner, the majority of them (58.1%, $n = 97$) stated that their husband/partner provided support most of the time or always. All but two mothers responded as to how satisfied they were with the support and/or assistance they received, with their answers ranging across the categories from very dissatisfied (5.1%, $n = 10$), generally dissatisfied (11.6%, $n = 23$), somewhat dissatisfied (13.6%, $n = 27$), to somewhat satisfied or generally satisfied (27.8%, $n = 55$ for both categories), and very satisfied (14.1%, $n = 28$). The three most frequent sources of support indicated by these mothers were the target child (97%),

other children in the home (94.5%) and their husband/partner (91%). Although healthcare providers were listed as sources of support by 107 (53.5%) of the mothers, 24 (22.4%) of these respondents indicated that they rarely received support from them. Almost all the mothers (94%, $n = 188$) reported that there were family responsibilities or duties that the child usually performed, and 81.9% ($n = 163$) of the 199 mothers who responded stated that their children did additional things when the mothers had flare ups.

Child

During their mother's flare ups, 59.3% ($n = 118$) of the 199 children who responded indicated that they had received support. Approximately half of these youths ($n = 175$) reported that they were generally satisfied (26.9%, $n = 47$) or very satisfied (22.9%, $n = 40$) with the support or assistance that they received. However, a sizable number said that they were not. Eight percent ($n = 14$) of them stated that they were very dissatisfied, 6.9% ($n = 12$) said that they were generally dissatisfied, 14.9% ($n = 26$) reported being somewhat dissatisfied, and 20.6% ($n = 36$) indicated that they were only somewhat satisfied with the support that they received. Moreover, 81 or 40.7% of the 199 children reported that they had received no support. For the 118 children who indicated that they received support, the three most frequent sources noted were fathers (biological, step-, or adoptive) (70.3%), siblings (44.9%), and friends (35.6%). All but two of the 199 children who responded stated that they had family responsibilities or duties they usually perform at home. Sixty-eight percent of them ($n = 136$) indicated that during their mother's flare ups, they did additional things for her or the family.

Parent/Child Relationship

Mother

Eighty-three percent ($n = 166$) of the mothers reported that they had a very or extremely close relationship with the child in this study. One mother, however, indicated that she was not close at all to her child.

Child

Approximately seventy five percent ($n = 149$) of the children reported that they were very or extremely close with their mother, with only two children stating that they were not close at all to their mothers. Significant differences in responses were not found by age or sex. More than three-fourths (77.5%) of the 102 boys ($n = 79$) and 71.4% of the 98 girls who responded ($n = 70$) reported that they were very or extremely close to their mothers. For the 95 youths aged 11-14, 77.9% ($n = 74$) stated that they were very or extremely close to their mothers; 71.4% ($n = 75$) of the 105 youths aged 15-17 years reported the same.

Perceived Changes in Child's Life Due to Mother's Illness

Both the mother's and youth's survey contained questions that asked if there had been any changes in the child's life since the mother's illness. The areas of change referred to included school-related aspects (attendance, grades, activities), friends, activities outside of school, hobbies, and leisure behavior. The findings are presented in Table 5. As can be seen, with the exception of children in the 15-17 year-old group, both mothers and 11-14-year-old children reported that activities outside of school was the area where the most change had occurred in the child's life. Thirty-one percent of the 15-17 year-old youth ($n = 105$) stated that the biggest change had occurred with friends, with outside activities as the next most frequent area of change.

Table 5

Mothers' and Children's Reported Changes in Child's Life Due to Mother's Illness

Group Providing Assessment	Percent of group reporting there had been a change in these categories						
	School Grades	School Attendance	School Activities	Friends	Outside Activities	Hobbies	Other
All children							
Mothers	31.7	19.1	25.6	30.2	<u>44.4</u>	22.2	34.3
N	199	199	199	199	198	194	166
Children	15.2	10.1	14.6	24.6	<u>32.7</u>	17.2	16.2
N	198	199	198	199	199	198	185
Male children							
Mothers	28.7	13.9	17.8	26.7	<u>41.6</u>	19.0	29.2
N	101	101	101	101	101	100	89
Males	13.7	10.8	9.8	17.6	<u>23.5</u>	10.9	10.4
N	102	102	102	102	102	101	96
Female children							
Mothers	34.7	24.5	33.7	33.7	<u>47.4</u>	25.5	40.3
N	98	98	98	98	97	94	77
Females	16.7	9.3	19.8	32.0	<u>42.3</u>	23.7	22.5
N	96	97	96	97	97	97	89
11-14 Year-old children							
Mothers	34.7	21.1	29.5	31.6	<u>54.3</u>	27.5	32.9
N	95	95	95	95	94	91	79
11-14s	12.8	11.7	12.8	17.0	<u>39.4</u>	16.1	13.5
N	94	94	94	94	94	93	89
15-17 Year-old children							
Mothers	28.8	17.3	22.1	28.8	<u>35.6</u>	17.5	<u>35.6</u>
N	104	104	104	104	104	103	87
15-17s	17.3	8.6	16.3	<u>31.4</u>	26.7	18.1	18.7
N	104	105	104	105	105	105	96

Underlined values are the highest percentage for each group.

Parentification

The Parentification Questionnaire – Youth (PQ-Y) was responded to by 200 children. Chronbach's alpha calculated for this sample of children was .78. This indicates a moderate index of internal consistency, thereby enabling the PQ-Y data to be used as a reliable measure of parentification for group purposes. However, forty-three children did not answer all 20 questions. As noted in Chapter 3, following the recommendation by Jurkovic (the co-author of the PQ-Y), the sample mean for the specific missing item was used to replace the missing item score. As seen in Table 6, using this procedure, the resulting PQ-Y mean Total Score was 7.14 ($SD = 3.89$), and the range of parentification scores for the youths in the study was 0-18. The PQ-Y mean score for females was 7.97 ($SD = 4.29$); for males it was 6.33 ($SD = 3.29$). As would be expected, the older youths, aged 15-17, obtained a higher mean PQ-Y Total Score (7.71, $SD = 3.93$) than did those who were aged 11-14 years (6.50, $SD = 3.78$).

Study question 1 asked whether children's parentification scores differed significantly by the children's age or sex. To assess whether the PQ-Y Total Score differed significantly by age, one-way analysis of variance (ANOVA) of the PQ-Y Total Scores by youths' age grouped into two levels (11-14, 15-17) was conducted and yielded a statistically significant result of $F(1, 199) = 4.92, p = .028$. To assess whether there was a significant difference in the mean PQ-Y Total Score by sex, an ANOVA also was calculated. This result also was statistically significant, $F(1, 199) = 9.27, p = .003$. As indicated, significant differences were obtained by youth's age and sex, with older children and girls obtaining higher PQ-Y Total Scores.

Table 6

Parentification Scores (with Means Substituted for Missing Data)

Child Group	<i>N</i>	Mean	Standard Deviation	Min	Max	Range
Males						
11 to 14	48	6.13	3.28	1.00	13.00	12.00
15 to 17	54	6.51	3.32	1.00	16.00	15.00
All Males	102	6.33	3.29	1.00	16.00	15.00
Females						
11 to 14	47	6.88	4.23	0.00	18.00	18.00
15 to 17	51	8.98	4.14	2.00	18.00	16.00
All Females	98	7.97	4.29	0.00	18.00	18.00
All Children						
11 to 14	95	6.50	3.78	0.00	18.00	18.00
15 to 17	105	7.71	3.93	1.00	18.00	17.00
Total Sample	200	7.14	3.89	0.00	18.00	18.00

Relationship of Parentification to Selected Study Variables

Mothers' Illness

Study Question 2 asked whether children's parentification scores were significantly related to selected characteristics of the mother's chronic illness (i.e., length of illness and severity of symptoms, or cyclic nature of the illness).

Pearson product-moment correlations were calculated to assess the relationship between the youths' PQ-Y scores and length of diagnosed illness and severity of symptoms. As seen in Table 7, the youths' parentification scores did not correlate significantly with their mothers' length of illness or reported severity of symptoms. Given the extent of inconsistencies in the mothers' responses concerning flare ups ("do the symptoms appear as flare ups and remissions", "how often", and "if so, how long"), it was decided to not analyze the relationship of the PQ-Y score to the reported incidence of flare ups.

Table 7

Relationship of Mother's Length of Illness and Severity of Symptoms to Child's PQ-Y Score

Characteristic Child Group	<i>df</i>	<i>r</i>	<i>p</i>
Length of Illness			
Males	100	.212	.033*
Females	94	-.045	.663
11 to 14	92	.004	.969
15 to 17	102	.056	.572
All Children	196	.052	.469
Severity of Symptoms			
Males	100	.080	.427
Females	96	.057	.574
11 to 14	93	.152	.142
15 to 17	103	.046	.643
All Children	198	.081	.256

*significant at $p < .05$

Next, to examine whether these findings might differ by sex or by age of the child, correlations were obtained for boys and girls and younger and older youths. The only statistically significant result obtained was between boys' PQ-Y Total Scores and their mothers' length of illness ($r(100) = .21, p = .033$ (two-tailed)). The longer mothers were ill, the higher their sons' PQ-Y Total Score. In contrast, the correlation between girls' PQ-Y scores and their mothers' length of illness was only $r(94) = -.045, p = .66$ (two-tailed), suggesting perhaps that daughters assumed family tasks at a younger age than sons.. There were no significant correlations obtained between the youths' PQ-Y Total Scores and the severity of their mothers' illness by sex or age of the youths, suggesting the influence of other factors on parentification in the home.

Mothers' Background Characteristics

Study Question 3 asked whether children's parentification scores were significantly

related to their mothers' educational level, age, or marital status.

Pearson product-moment correlations were calculated to assess the relationship between youths' PQ-Y Total Scores and their mothers' educational level and age. No statistically significant relationships were obtained with $r = .012$ and $.063$, respectively. Next, a series of ANOVAs were conducted to examine PQ-Y Total Scores by mother's educational level and marital status, each divided into two groups. As seen in Table 8, no statistically significant results were obtained. In addition, no significant results were obtained when similar analyses were conducted separately for both boys and girls and for younger and older youth.

Table 8

ANOVA Results Examining Child's PQ-Y Score by Mother's Educational Level and Marital Status

Characteristic	<i>df</i>	<i>F</i>	<i>p</i>
Education Level	1, 199	.022	.883
< 2 yrs college ($n=97$, $M = 7.10$, $SD = 3.94$)			
2 or more years ($n=103$, $M = 7.18$, $SD = 3.87$)			
Marital Status	1, 199	2.33	.129
No Partner ($n=49$, $M = 7.87$, $SD = 4.06$)			
Partner ($n=151$, $M = 6.90$, $SD = 3.82$)			

Mothers' Perceived Support

Study Question 4 asked whether children's parentification scores were significantly related to the mothers' perception of availability of and satisfaction with sources of support.

Pearson product-moment correlations were computed to assess the relationship between

the youths' PQ-Y Total Scores and their mothers' perceived amount of support from her husband/ partner and/or child in the study, and her satisfaction with the support she received.

The correlation of the youths' PQ-Y Total Scores with their mothers' satisfaction with sources of support was statistically significant with $r(196) = -.16, p = .025$ (two-tailed). The lower the mother's reported satisfaction with the support or assistance that she received, the higher the child's PQ-Y Total Score. An one-way ANOVA comparing PQ-Y Total Scores with two levels of the mother's satisfaction with sources of support - very, generally, or somewhat dissatisfied vs. very, generally, or somewhat satisfied – also was significant, $F(1, 196) = 5.36, p = .022$. The group of children whose mothers reported being very, generally, or somewhat dissatisfied had a significantly higher mean PQ-Y score ($M = 8.10, SD = 4.40$) than did those whose mothers reported being more satisfied ($M = 6.72, SD = 3.62$).

Next, to examine whether these findings might differ by age or by sex of the child, separate correlations were obtained for boys and girls and for younger and older youth. As shown in Table 9, the only statistically significant result obtained was for children aged 11 to 14. The less satisfied that mothers were with their perceived sources of support, the higher their 11-14-year-old children's PQ-Y Total Scores. ANOVAs were conducted to compare PQ-Y Total Scores with the two levels of mothers' satisfaction for each subgroup of children. Two statistically significant results were found, indicating that girls, $F(1, 97) = 4.38, p = .039$, and children aged 11 to 14, $F(1, 94) = 9.51, p = .003$, had significantly higher PQ-Y Total Scores when their mothers were dissatisfied than when they were satisfied. For girls, the mean PQ-Y Total Score for dissatisfied mothers was 9.35 ($SD = 4.90$) versus 7.40 ($SD = 3.90$) for satisfied mothers. For children aged 11 to 14, the corresponding means were 8.27 ($SD = 4.43$) and 5.76 ($SD = 3.22$).

Table 9

Relationship of Mother's Satisfaction with Support to Child's PQ-Y Score

Child Group	<i>df</i>	<i>r</i>	<i>p</i>
Males	98	-.167	.097
Females	96	-.163	.110
11 to 14	93	-.252	.014*
15 to 17	101	-.071	.475
All Children	196	-.160	.025*

*significant at $p < .05$

Additional Analyses

An additional set of analyses was conducted in an attempt to better understand these parentification findings. Youths' PQ-Y Total Scores were compared to their reported feeling of support, the mother and child's reported perceived burden of the mother's illness, and how close each described their mother/child relationship.

Children's Perceived Support

The correlation of PQ-Y Total Scores with the youths' satisfaction with sources of support was significant, $r(173) = -.37, p < .0005$ (two-tailed), indicating that the higher the youth's satisfaction with sources of support, the lower his/her PQ-Y score. An ANOVA comparing youths' PQ-Y Total Scores with their satisfaction with sources of support (responses divided into two categories, somewhat, generally, or very dissatisfied and somewhat, generally, or very satisfied) also was significant, $F(1, 174) = 9.64, p = .002$. Those children who reported that they were somewhat, generally, or very dissatisfied with their sources of support obtained a significantly higher mean PQ-Y Total Score ($M = 8.64, SD = 4.16$) than did those children who reported that they were somewhat, generally or very satisfied with the support they received ($M = 6.71, SD = 3.58$).

Perception of Illness as Burdensome

The correlation between children's PQ-Y Total Scores and how burdened their mothers

reported feeling due to their illness was statistically significant, $r(197) = .15, p = .034$ (two-tailed), indicating that the more burdened a mother felt by her illness, the higher her child's PQ-Y Total Score. A significantly stronger correlation was obtained between the children's PQ-Y Total Scores and how burdened they felt by their mother's illness, $r(196) = .38, p < .0005$ (two-tailed). Therefore, the more burdened the children felt by their mothers' illness, the higher their PQ-Y Total Scores.

To examine this finding further, an ANOVA was performed. The dependent variable was youth's PQ-Y Total Score and the independent grouping variable was how burdened the child felt by her/his mother's illness. Responses were divided into two categories. Those children who reported that they felt not at all, or only slightly or somewhat burdened, had a significantly lower mean PQ-Y Total Score ($M = 6.15, SD = 3.30$) than did those children who reported that they were very or extremely burdened ($M = 8.66, SD = 4.24$) with $F(1, 199) = 21.98, p < .0005$.

Closeness of Mother-Child Relationship

Mothers' Perception

A statistically significant correlation, $r(198) = -.29, p < .0005$ (two-tailed), also was found between children's PQ-Y Total Scores and their mothers' reported closeness to the target child. Children of mothers who reported closer relationships with their children had lower PQ-Y Total Scores. A one-way ANOVA comparing youths' PQ-Y Total Scores and their mothers' perceived closeness to her child, with ratings divided into two categories (not at all, only slightly, or somewhat close vs. very or extremely close) was statistically significant ($F(1, 199) = 6.94, p = .009$). The children of mothers who reported being not at all, only slightly, or somewhat close to their child had a significantly higher mean PQ-Y Total Score ($M = 8.72, SD = 4.68$) than did those of mothers who reported being very or extremely close to their children ($M = 6.81, SD = 3.64$).

Correlations also were computed to assess whether this relationship of youths' PQ-Y Total Scores to mothers' perceived closeness to their child differed according to the child's sex and age. A significant result was obtained for the female youth, $r(96) = -.42, p < .0005$ (two-tailed), indicating that the closer to her daughter the mother reported feeling, the lower the child's PQ-Y Total Score, whereas the correlation for sons was not significant, $r(100) = -.15, p = .15$ (two-tailed). When age levels were compared, a significant correlation was obtained for both 11-14 year-olds, $r(93) = -.34, p = .001$ (two-tailed), and for 15-17 year-olds, $r(103) = -.24, p = .014$ (two-tailed). The closer to her child a mother reported feeling, the lower his/her PQ-Y Total Score across the sampled age range.

Children's Perception

Similarly, a statistically significant correlation, $r(198) = -.36, p < .0005$ (two-tailed), was found between youths' PQ-Y Total Scores and their reported closeness to their mother. Children who reported that they had a very close relationship with their mother had lower PQ-Y Total Scores. An ANOVA comparing youths' PQ-Y Total Scores and their perceived closeness to their mother with ratings divided into two categories (not at all, slightly, or somewhat close vs. very or extremely close) was significant ($F(1, 199) = 26.31, p < .0005$). The mean PQ-Y Total Score for the group of children who reported feeling closer to their mother ($M = 6.36, SD = 3.42$) was significantly lower than the mean PQ-Y Total Score of those children who reported feeling less close to their mother ($M = 9.41, SD = 4.31$).

Summary

The majority of the 200 participating mothers in this study were Anglo/Caucasian, had some college or a Bachelor's degree, were not working outside the home, had FM rather than RA, and had their illness for an average of 12.87 years. The majority (79.5%) reported experiencing daily symptoms, with 61% rating them as very to extremely severe,

and feeling very or extremely burdened by their illness. The more burdened mothers felt by their illness, the more burdened the children felt too. More than half of the mothers indicated that they were satisfied with the support and/or assistance they received and stated that their husband/partner provided some type of support most of the time or always. However, almost all of the mothers noted that the child in the study was the most frequent source of support. Although the mothers reported that their illness had affected their relationship with the target child in both positive and negative ways, the majority of them (83%) said that they felt very to extremely close to the child in the study.

The majority of the participating children also were Anglo/Caucasian, attended 11th grade, were not employed, and reported having no health problems. However, 85 or 42.5% did note health problems. In addition, all but 22 (11.1%) reported feeling some degree of burden by their mother's illness, with 38.9% ($n = 77$) stating that they felt very or extremely burdened, and 29.8% of the children ($n = 52$) reporting that they were not satisfied with the support that they received during their mother's flare ups of illness. During these times, they noted that they assumed additional family responsibilities and duties. Although a majority of the youth (65.8%) noted that their mother's illness had affected them in negative ways, a sizable percentage (40.7%), mostly girls, reported it had affected them in positive ways. Nearly three-fourths of the children ($n = 149$) indicated that they were very or extremely close to their mother.

Both the mothers and children reported changes in the child's life due to the mother's illness, with most referring to activities outside of school except for those ages 15-17. These older youth reported the greatest change was with friends, particularly not being able to spend as much time with them. Mothers of 15-17 year-olds also reported other changes affecting themselves such as having less physical stamina to participate in family activities, having less money to do things together as a family, needing more help in the home, and

having to ask the older children to provide more sibling care.

In assessing the posed study questions, the following findings were obtained: No statistically significant relationship was found for the total group between the reported extent of the youth's parentification and the type of the mother's illness (RA or FM), the length of the illness, or the severity of symptoms she reported. However, a significant correlation was obtained for boys between their PQ-Y Total Scores and their mothers' length of illness. The longer their mothers had been ill, the higher the sons' PQ-Y Total Score. Unfortunately, analysis of the relationship between a specific characteristic of these illnesses, flare ups, could not be conducted due to the extent of inconsistencies in the mothers' responses.

No statistically significant relationships were obtained overall between the youths' parentification scores and their mother's educational level, age, or marital status for the total group or when analyses were conducted separately for boys and girls and for younger and older youth.

Statistically significant relationships were found between the reported extent of parentification and the youth's age (the older the child, the higher the PQ-Y Total Score) and the youth's sex (girls obtained a higher mean PQ-Y Total Score than did boys). Youths whose mothers reported low satisfaction with the assistance or support that they received also obtained higher parentification scores. Lower parentification Total Scores were reported by those youths who expressed higher satisfaction with their sources of support and by those youths who reported that they had a very close relationship with their mothers. Youths whose mothers reported having closer relationships with them also obtained lower parentification scores.

In the following chapter, these findings are discussed and an attempt made to integrate them and suggest their implications for family professionals in practice and research.

Chapter 5

DISCUSSION AND CONCLUSIONS

The primary purpose of this study was to explore the relationship between selected characteristics of mothers with fibromyalgia and/or rheumatoid arthritis and the extent of parentification of their preadolescent and adolescent children. In this chapter, findings from the four posed research questions are discussed relevant to existent research and theory. Implications of the findings for practice and suggestions for further research also are presented.

The Major Research Questions

Parentification of the Child by Age and Sex

Age of Child

It is expected that older children will have more responsibilities; this is an essential part of adolescent development and this was true for this study's participants. Older children (age 15-17) obtained higher parentification scores than did the younger children (11-14 years). As adolescents become older, increased demands on them may foster increased parent-child discord that could be reflected in parentification scores (Korneluk & Lee, 1998). If the tasks/demands made on the child are age-appropriate, not excessive, and acknowledged by parents, then parentification is viewed as a normal, healthy part of the child's maturation process.

Sex of Child

As noted by many across the centuries, women have been assumed by society to be nurturers and caregivers, thereby placing female children at a greater risk of parentification than males (Dale & Altschuler, 1999; London, 1989). In addition, "[w]hen the ill parent is the same gender, the child [is] more likely to assume some of the parent's roles" (Pedersen

& Revenson, 2005, p. 413). The present study's findings support this research; daughters obtained significantly higher parentification scores than did sons. However, girls often are described as more mature than boys. This may lead to them being given more responsibilities which in turn acts to support that view.

According to Winton (2003), at the adolescent stage of life development, girls should be focusing on separating themselves from their family and spending more time on self-development and peers. This requires that both mother and daughter develop new and different responses as they move through the adolescent stage. The relationship that a daughter has with her mother provides the daughter with a basis for development of her identity, autonomy, and connection (Spira & Kenemore, 2000). Typically, daughters move through the adolescent stage from being dependent on her mother to being interdependent with the mother. However, the mother's illness may disrupt this developmental transition and it often causes the daughter to take over the mother's role in the family. Instead of them forming an interdependent relationship, the mother now becomes dependent on the daughter – a reversal of roles. An additional task for these daughters is to be flexible enough to take on the mother's role when it is needed and yet, to relinquish this role when the mother's illness is stabilized and she is able to resume her activities. Those who are unable to do this may feel displaced and unneeded by their mothers.

Parentification and Characteristics of Mother's Illness

Length of Illness

One of the major research questions examined the relationship between the extent of parentification of children and characteristics of their mother's illness (i.e., length of illness and severity of symptoms). Although the correlation between the mothers' length of the diagnosed illness and youths' parentification scores was not significant for the total sample, boys' parentification scores were significantly higher for those whose mothers had

been ill longer. According to family development theory, adolescence is a stage when a variety of developmental changes such as sexual identity, career development, intimacy, physical maturation, emotional separation from parents, and establishing a personal set of values and ethical principals occur (Chapin, 2000). During this transitional time, norms and roles of both parent and child generally change so that children can achieve greater independence and self-reliance, but family and societal norms have been found to differ for sons and daughters. As children become older, they may strive to balance the level of contributions they make to their family with those related to their individual development. This may be perceived as breaking away from the parent-adolescent relationship. When mothers have a lengthy illness, it may be more difficult for their children to seek autonomy and independence. Perhaps it is this struggle between achieving adolescent independence and meeting the mother's illness demands that creates a stronger sense of family burden for sons than daughters given stronger societal expectations for independence in sons. Or perhaps sons feel more uncomfortable with physical caring for their mothers because they feel it violates their emerging masculine gender role (Santrock, 1993).

Severity of Symptoms

Sixty-six percent of the mothers rated the severity of their symptoms as very to extremely severe and nearly 80% of the mothers experienced these symptoms on a daily basis. However, no significant correlation between mothers' reported severity of symptoms and parentification scores was obtained. Since most mothers reported the severity of their symptoms as very to extremely severe, the range of these scores may have been too restricted for this size sample to produce a significant result.

“One of the confusing observations in FMS research is pervasiveness of inconsistent findings” (Okifuji & Turk, 2002, p. 136). This is true for FM symptom severity. Murray & Murray (2006) found lower FM symptom severity scores reported by people who had an

education level of 17 years or more, were employed, had a household income level of \$60,000 or higher, and were aged 58 or older. However, in their study of clinical symptoms of FM (pain, fatigue, depression, and anxiety), Martinez, Panossian, Gavioli, and Gozzano (2005) found no significant association of these symptoms with family income or educational status.

Parentification and Characteristics of Mother's Background

Mother's Education Level

Significant relationships were not found between the mothers' educational level and their children's parentification scores. Several researchers had noted an association between lower formal education level and greater severity of RA and FM symptoms (Brekke et al., 2003; Eberhardt & Fex, 1995; Murray & Murray, 2006; Pedersen et al., 2006; Pincus & Callahan, 1993; Verbrugge et al., 1991; Vliet Vlieland et al., 1994; Young, 1992). It is assumed that those with more education seek additional information pertaining to their illness in order to advance their understanding of their condition. However, this study sample had very few participants with less than high school education. Moreover, those with more education have more access to healthcare. Only 22% ($n = 25$) indicated that they had no post-high school education and the remaining participants' ($n = 175$) educational experiences ranged from taking some vocational or post-high school training through attaining doctoral degrees. Therefore, ANOVAs were conducted for two educational levels, those who had less than two years of college and those with two years or more of college. No statistically significant differences were obtained.

Mother's Age

The correlation between mother's age and the child's PQ-Y score was .063 ($p = .38$), which was not statistically significant. An ANOVA analyzing parentification scores by mothers' age divided into three levels (less than 37 years, 37 to 48 years, greater than 48

years) also was conducted and no significant results were obtained. The group sizes differed greatly and this may have been a contributing factor. To have participated in this study, mothers needed to be between the ages of 25-57. This age range specifically was chosen because it encompasses the major child-rearing years of women's lives. During this stage, mothers also may work and be married. Adding a chronic illness to this stage of life affects the ability of women to meet their various role demands. No research has been found, however, pertaining to parentification as related to mothers' age.

Mother's Marital Status

Research has shown that children whose parents were divorced experienced greater parentification because they were required to accept more family responsibilities as well as care for their ill mother (Chase, 1999; Goglia, 1982; Jurkovic, Thirkield et al., 2001; London, 1989; Peris & Emery, 2005; Winton, 2003). The absence of a parent through divorce creates changes in the family structure and more roles need to be filled by fewer people (Spira & Kenemore, 2000). However, the present study findings did not show this. This may have been due to the large difference between the number of mothers who were partnered ($n = 151$) and those who had no partner ($n = 49$). In addition, data were not collected with regard to the length of time a spouse or partner had been absent or the roles of other adults in the household who may have assumed some of the caregiving roles.

Relationship of Parentification to Mother's Satisfaction with Support Received

When social support provides a positive influence on the management of the mother's illness, the effects of the mother's illness have been shown to be less severe. A mother's perception of the adequacy of support received, rather than the amount and type of support, may better determine the outcome of her health. In this study, mothers who reported less satisfaction with the support or assistance they received had children who reported greater parentification. This may indicate that children are trying to compensate for the lack of

support in their mothers' lives or that these mothers make more demands on them. Nearly all of the mothers (94%) stated that their children helped at home and when they were ill, 82% of the mothers reported that their children did additional things for the family as a whole and for them personally. In this study, the additional tasks consisted of instrumental support such as providing more sibling care and grocery shopping, as well as personal physical care of the mother. However, the receipt of instrumental support has been found to be associated with increased depression (Penninx et al., 1998), as it may be viewed by the mother as reflecting her inability to meet her role demands.

Additional Findings Related to Parentification

Child's Satisfaction with Sources of Support

In this study, the amount of parentification that the children reported that they were experiencing was related to their degree of satisfaction with their perceived support. Those children who reported more satisfaction with their sources of support said that they felt less parentified. It might be ventured that even if children have the same family demands, those without adequate support may perceive these demands more negatively. This reflects back to the definition of destructive parentification. If the children's responses to parental needs are not acknowledged or supported, then parentification is considered to be destructive.

Changes in Child's Life

Some studies have reported that the areas most likely to be affected in young caregivers' lives are family life, school performance and attendance, time with friends, and social and recreational activities (Child Development Institute, n.d.; Lackey & Gates, 2001; Pakenham et al., 2006). These findings were supported in this study, with the most change reportedly occurring in activities outside of school for all youths except for those aged 15-17. Mothers stated that activities outside of school changed for their child in the following

ways: “decreased activities due to [my] feeling ill”, “limited to 1 activity a week due to my fatigue”, “curtailed”, “not always able to take him places or have money to do things”, “she worries about leaving me alone”, and “busy cooking, cleaning, caring for me, not much time for anything but school.”

For those children aged 15-17, the greatest reported change was in the area of friends. Friendships are necessary to provide support and promote positive adolescent development through enjoyment as well as intellectual, moral, and artistic stimulation (Walker & Sage, 2006). However, young caregivers “are less likely to than most children to have their friends visit them at home because of discomfort regarding their parent’s illness” (Pakenham et al., 2006, p. 115). With regard to their child’s friendships, mothers in this study stated that “at times he avoids them. Embarrassed or didn’t know how to explain why I was sick a lot”, “some of his friends don’t know and/or can’t understand [illness]”, “I feel bad when he can’t go outside with friends and they can’t come inside either”, [she] relies on friends to take her mind off things. Brings friends over to help her with housework”, “She doesn’t go out with her friends as much. She always waits to see how I am first – bad days she usually stays home”, “limits friendships to school time as after school time activities with friends would tax my physical resources”, and “I limit my child’s socialization with friends based on how I am feeling and if I can tolerate a friend in my home or take my child to the friend’s house”. Children who are responsible for caring for their ill parents are more likely to not receive support from family and/or friends. However, support is essential for children to experience a sense of well-being.

Burden Associated with Mother’s Illness

Greater parentification was expressed by the child when the mother reported that she felt more burdened by her illness and when the child reported feeling more burdened by the mother’s illness. From a family systems perspective, changes in roles within the

family cause shifts in the division of labor and instability in the family system. From a family developmental perspective, for children to care for ill mothers requires “task demands that exceed their developmental capabilities” (Peris, 2006, p. 7). In turn, these changes can lead to learned helplessness, poor self-efficacy, low self-esteem, anxiety, and depression. The following are some of the responses to the youth’s survey question “Do you think that your mother’s illness has affected you in any bad (negative) or troublesome ways?” that may reflect why children feel burdened by their mothers’ illness: “little stressed, sad, frustrated, impatient when she gets flares”, “watch my mom sit in pain, nothing I can do about it”, “worry that her condition will worsen”, “sometimes I try to help her so much that it makes me feel neglected”, “her disease has ruined most of the fun in my life”, “she is unable to work so there is little money”, “she makes me not want to complete what I do and not feel good about myself”, “given me (& everyone) bigger loads of stress”, “when she is ill I usually have more responsibility and feel like I have to take care of her”, “frustration that comes with never knowing how mom is going to feel on any given day”, “seeing my mom go through such pain and not being able to do anything upsets me in such a way that I can’t express”, “I stress about her well being and I worry all the time about her. It sometimes just adds to the everyday stress”, “it has made me a depressed, sad miserable child who fails school, has no friends he can trust”, and “sometimes I feel like I have no mother”.

Mothers who felt burdened by their illness believed that their child felt the same way. This was regardless of the child’s age or sex. When mothers reported feeling burdened by their illness, their children did so as well. And the greater the burden of the illness experienced by the mother, the more the child felt burdened by the mother’s illness. When mothers are experiencing an exacerbation of the illness and feel less able to do things, they may ask for more help from the child. In turn, the child’s burden from the illness increases

too. These feelings from the child may be a direct result of what the mother expresses while she is ill and the number of demands made on the child during this time. Also, if children have close relationships with their mothers, they may instinctively “feel” the mother’s burden and know when she is not feeling well without her having to express this. Some mothers stated [she] “has learned my body language” and [he] “can read my body movements”.

It should be pointed out, however, that both mothers and children noted a number of positive effects of the mothers’ illness such as the children becoming more compassionate, empathetic, and caring toward other people, and the family becoming closer in general. Several children stated that their mothers’ illness has made them more spiritual. Two children reported efforts to increase community awareness of this illness. One child started a fundraiser to help aid FM research and the other child chose FM as a topic for a biology report that was presented to her class.

Closeness of Mother–Child Relationship

Developmental changes that typically occur during adolescence include the transformation of the parent-child relationship from one with camaraderie to one that exhibits a decrease in time spent with parents, family cohesion, and closeness and an increase in conflict (particularly in early adolescence) and in emotional distancing (Buist, Dekovic, Meeus, & van Aken, 2002; Seiffge-Krenke, 1999). In the mother-child dyad, conflict with daughters is reported to be more common than with sons. However, according to Seiffge-Krenke (1999), it is more characteristic for mother-daughter relationships to experience both closeness and conflict. In the present study, mothers who reported closer relationships with their children had children who reported feeling less parentified. A biased response might be expected from the mother with regard to the question, “How close a relationship do you have with the child in this study?” However,

in a closer relationship, the mother may be more sensitive to the child's needs and not demand inappropriate responsibilities or she may be more aware of the manner in which she requests that tasks be done. The closer a mother reported feeling toward her child, the less parentified the child reported feeling regardless of his/her age. In addition, the closer the mother said she felt to her daughter, the less parentified her daughter scored. This did not hold true for sons, perhaps in part due to the generally lower parentification scores sons obtained overall. Children who reported that they were very close to their mothers generally obtained lower parentification scores. Perhaps the closer they feel to their mother, the less they believe that chores and duties are unfair. In this study, there was only one mother who responded that she was not close to her child at all; this child reported the most parentification in this study and responded as parentified on 18 of the 20 questions on the PQ-Y.

Often parents believe that they become less important in the healthy development of their adolescents, but parent-child ties are strongly related to adolescent well-being. Parents need to provide warm, supportive, quality relationships for their adolescent children so that they can develop strong social competencies. This is extremely important because “[q]uality social relationships and good social skills play a role in healthy psychological development, academic success, and even later life relationships, such as marriage and parenting” (Child Trends Research Brief, July 2002, p. 3). It is important to recall that in this study, children aged 15-17 reported that the biggest change in their activities related to the mothers' illness was in the area of activities with friends.

Implications for Practice

Fibromyalgia

The majority of participants in this study had fibromyalgia and, therefore, the emphasis of this study has been on mothers with FM and on their families, particularly their

adolescent children. From a family systems perspective, reciprocal patterns of interaction predict that when treating any individual in the family, changes will occur that will affect the remaining family members (Patterson, 1991). Innovative programs and practices need to incorporate levels beyond that of the individual and include the family and community. From a family development perspective, while treating the individual is imperative, it is important to work with all family members so that each of them can achieve the developmental tasks necessary for them to transition successfully to their next stage.

Individual Interventions

“The fibromyalgia syndrome presents with a particularly unique and challenging symptomatology that makes it one of the most difficult and frustrating of all rheumatic diseases for patients, significant others, [family], and their health care practitioners to manage” (Preece, 2001, p. 96). The multifaceted nature of FM suggests that development of multimodal, individualized treatment programs may be necessary. Predominant responses from both mothers and children in this study centered around the inability of the mothers to partake in family events and provide transportation for the children due to her pain, extreme fatigue, and “brain fog”. Therefore, these programs should aim at improving the debilitating symptoms of the illness so that mothers can resume their roles in the family and their interactions with family members. The programs also should promote aspects of exercise, medication education (alternative, non-pharmaceutical, and prescription), body pacing activities and ergonomics, occupational therapy, physical therapy, and stress management techniques such as emotional well-being and cognitive-behavioral therapy (Adams & Sim, 2005; Bernard et al., 2000; Da Costa et al., 2005; van Koulil et al., 2007; Orr et al., 1989; Rooks, 2007; Wallace et al., 2005). If recent research on subgroups of FM patients is correct, then programs developed for FM sufferers may need to address this issue and offer more tailored agendas (Koulil et al., 2007; Turk, 2002).

Family Interventions

Higher levels of social support (social connectedness) have been associated with better health (Cronan & Bigatti, 2003; Hughes, Nosek, Howland, Groff, & Mullen, 2003). This holds true for the ill person and those related to her/him. Millea and Holloway (2000) have noted that an excellent way to provide support to mothers with FM and their families is to encourage attendance in support groups and online chat rooms. By incorporating a close family member such as the adolescent or significant other, they can learn about the illness, improve communication or interactions, and possibly ease some of the caregiving burden through new knowledge (Martire & Schulz, 2007). From a systems perspective, when family members cannot get clear facts as to why a family member is ill, the system becomes frozen in place, structural reorganization is not possible, and the system's boundaries are not able to be maintained (Buehler & Pasley, 2000). In this study, some children expressed their doubt about whether their mothers really were ill. "I think that she pretends to be sicker than she seems. My dad thinks FM is not that bad and she exaggerates." By having family members attend support groups, they will see how other people function with FM and learn that this is a valid illness.

Recently, it has been suggested that reciprocity may be an important element in intervention programs. "[M]erely receiving support may not be as potent as mutual exchanges of support" (Walker & Sage, 2006, p. 8). Interventions also may be more effective if recipients' support needs are more closely matched with potential sources of support. For example, "[s]ome people, particularly those who are highly introverted or independent, may not desire support, even if their networks are relatively small. In general, women are more likely than men to use social support as part of their efforts to cope with stress and adversity" (Walker & Sage, 2006, p. 8).

Community and National Interventions

Social support from both within and outside the family system may moderate adjustment to illnesses for adults (Pedersen & Revenson, 2005). Patients often reach out to their physicians for social or emotional support (Riessman, 2000). However, physicians are usually not trained to provide this type of support and may become frustrated and see these patients as difficult. This is especially true for FM patients who have a multitude of questions that currently have no answers (Walker, Katon et al., 1997). Additionally, patients with FM want physicians to acknowledge their pain and suffering as credible and real, but this also frustrates the doctors because if these symptoms are acknowledged, the physicians have no guaranteed treatment to offer their patients (Geenen & Middendorp, 2006; Werner et al., 2004). Before interventions can be implemented, the illness and the ill person must be acknowledged and believed (Soderberg, Lundman, & Norberg, 1999; Sylvain & Talbot, 2002).

Community interventions need to enlist the support and backing of the local medical community to provide education and therapies. For example, many states in this country, including New Mexico, have arthritis self-help classes for FM and RA that ill patients and their significant other may attend. This is a community-sponsored event that is supported by the Arthritis Foundation. Recently, the National Fibromyalgia Association (NFA) announced that it is launching a nation-wide campaign to increase understanding of FM among patients, healthcare providers, and the public. This multifaceted campaign will include patient education materials, nationally broadcasted public service announcements, and an interactive Website – <http://www.fibrohope.org/>. This is the first exposure of this kind for FM and it is hoped that it will increase an understanding of this illness (NFA, 2007b).

Parentification

Young caregivers in the United States are an overlooked population when it comes to providing them with support. To date, this country has one program designed to help middle-school children who are caregivers. It is located in Palm Beach County, Florida, and is directed by Connie Siskowski (personal communication, May 25, 2007). The mission of this pilot project is “to recognize, support, and promote the awareness of dual role youth who are both students and young caregivers within their families” (American Association of Caregiving Youth [AACY], 2006). Services provided by this program include: young caregiver assessment, a support group for student-caregivers, information and education, linkages to community resources, caregiver skills training and communication, young caregiver camp or retreat, and respite (AACY, 2006).

The American Association of Caregiving Youth, the only organization of its kind, has been formed “to address the needs of pre-teens, teens, families, and professionals through education and awareness, research, and direct services in cooperation with social, educational, healthcare, government, and community corporations, organizations, and agencies on a local, regional, and national level” (AACY, 2007, p. 1). A second young caregivers’ project “Caregiving Youth Project of Pinellas” is scheduled for Largo, Florida, in the near future.

[P]eople faced with a serious illness need an available network of interpersonal relations on which they can count for both emotional sustenance and practical help during periods of pain, disability, and uncertainty. Children of ill parents serve on this frontline. In essence, then, they occupy a dual role in the adjustment process: as a primary provider of emotional and instrumental support to the ill parent and as a family member who needs (additional) support in the face of a major and often long-lasting life stressor.

(Pedersen & Revenson, 2005, p. 414)

Additional Suggestions for Programs of Support

The programs and practices described above focus on ways to support mothers with FM and their families. This researcher believes, however, that to strengthen these services, the mother also needs to be viewed as a person with a chronic illness. During the 1980s, much research was conducted in this area. By utilizing the knowledge and concepts gathered from this research and combining it with the current research on FM, stronger programs can be developed to meet the needs of the chronically ill mother and her family.

As mentioned in Chapter 2, developing a chronic illness is a life-changing event for both the mother and her family. It creates turmoil and change throughout all areas of their lives and often is accompanied by very strong emotions. Adolescence is known for being a time of turbulence and overwhelming emotions as well. If mothers become chronically ill during the adolescent stage of their children's lives, intense emotions can permeate the entire family system.

Chronic illness also is accompanied by a deep sense of loss and grief. The ill mother and her family must learn to adjust to the physical, social, and emotional loss of her. In addition, the family now needs to assume many of her roles and responsibilities. This forces them to experience more personal change and loss. The result is that when the mother becomes chronically ill, the entire family grieves and suffers deep losses. Since chronic illness is composed of a series of crises as the illness cycles through flare ups and remissions, these losses are experienced repeatedly and never cease.

The researcher believes that to develop strong support for parents and their children, individual and family programs should be designed. Programs for parents should incorporate topics on:

1. child and adolescent developmental stages

2. anger and stress management
3. how families communicate
4. adjusting to grief and continual loss
5. parenting education
6. marriage and couples counseling

Programs for children should provide topics on:

1. child and adolescent developmental stages
2. anger and stress management
3. how families communicate
4. adjusting to grief and continual loss
5. being a health care provider – how to lift, take temperatures, dispense medicines
6. caring for the home
7. cooking and nutrition
8. handling family finances
9. individual counseling

At some point, family counseling should be provided. Support programs should not be offered only once. Since chronic illness is ongoing and families change over time, these programs should be available continually to all members of the family.

Based on the findings of this study, it is recommended that chronically ill parents need to be guided to build support groups outside of their children. As children enter adolescence, they need to be able to pursue developmentally appropriate processes such as disengaging from parents. Schools should be a vehicle to offer counseling and support to children who are caregivers. In addition, to lessen the burden on their children, families of chronically ill mothers should be connected to general support services such as “Meals-on-Wheels”.

Suggestions for Future Research

This study has provided suggestions for additional research. A replication of this study using a sample of adolescents and their fathers with FM as well as one that includes greater diversity in ethnicity and social-economic status is recommended. Several males called or e-mailed the researcher stating that FM attacks their segment of the population and no research has been done in this area. Moreover, this study relied on self-report measures. Future research is needed that includes more in-depth measures such as individual interviews with all members of the family and focus groups, especially for children and youths, who are more likely to express themselves among other youth than when responding to an adult.

Currently, there are several areas of study in FM predominately from a medical or science point-of-view: alternative therapies for treatment, medications, pain, sleep, and comorbidity associated with FM. It is suggested that other more family-oriented areas be considered for further study, such as FM and the role of emotional precipitants, children with FM, coping styles of FM parents and their children, family clustering/inheritance of FM, types and sources of social support for children and adolescents, and resiliency of children and parents with FM.

To date, there are 28 research articles containing parentification in their titles. However, very few are linked with medical situations that affect the family. Five articles pertain to alcoholism and 1 each pertain to AIDS and HIV. No articles include parentification and its relationship to chronic illness, RA or FM, or parents with physical and/or mental disabilities.

In addition, although the PQ-Y is described as a psychometrically sound instrument for children and youth that has been used in numerous studies and has revealed important

variables such as “low self-esteem, risk behaviors, and parental alcoholism in a heterogeneous group of pre-adolescents and adolescents” (Godsall & Jurkovic, 1995, p.2), there still may be problems with this instrument in understanding parentification. The PQ-Y assesses the type of roles and responsibilities (expressive and instrumental) assumed by children in their families. However, it is not designed to capture the frequency or duration of these tasks or to ascertain how the participant feels about doing these tasks. Yet, without knowing the frequency or duration of responsibilities or how the child feels about completing these tasks, it is difficult to determine if there is destructive parentification. It is assumed that the higher the score on the PQ-Y, the greater the amount of parentification. A certain degree of parentification may be part of normal adolescent development. At what level (score) does this become a concern? The PQ-Y provides a quantified measure of parentification (Godsall, 1988), but it does not assess the type of parentification or the effect on the child. The researcher tried to account for this, at least in part, by directly assessing these factors.

There is a plethora of research studies pertaining to the extent and influence of social support for adults. However, little research has been conducted on the influence of such support on children. Lower support levels have been linked to poorer mental and physical health; in this study both mothers (55%) and children (42.5%) reported children's health problems. Peris (2006) stated that “the task of attempting to meet parental needs is sufficiently stressful to induce headaches, stomachaches, and other somatic symptoms” (p. 94). While there still is a “lack of knowledge about whether and how social support interventions work” with children, there is a professional consensus that “strengthening interpersonal and community ties is a promising resilience and development-promoting strategy for all children and families who are affected by mental health difficulties” (Walker & Sage, 2006, p. 3). This family systems approach also seems to be appropriate

for children and families with physical health problems. It is recommended that youth be helped to seek wider social networks that could include peers and other community people/groups.

While the United Kingdom and Australia have been conducting research on young caregivers in their countries for the past decade or more, children and adolescents in the United States who are living in families where there is a chronically ill parent are an overlooked population in research (Anderson & Smith, 2007; Shifren & Kachorek, 2003). There are no estimates on the hidden social and economic costs of unpaid caregiving supplied by children (Becker, 2007).

Summary

This study has provided a springboard for additional research regarding fibromyalgia and the effects on the family. For the 200 mothers and their pre-adolescent and adolescent children who participated in this study, the study findings suggest that when mothers are chronically ill, particularly with fibromyalgia, there appears to be greater parentification for: sons as the length of their mothers' illness increases, older children (age 15-17), daughters rather than sons, children of mothers who feel less satisfied with their sources of support and/or assistance, and children of mothers who feel more burdened by their illness. Parentification appeared less for children who reported more satisfaction with their sources of support, and whose mothers reported feeling closer to their children. This was especially evident for daughters when both they and their mother reported having a very close relationship. Additionally, when mothers feel burdened by their illness, they are more likely to report that their child feels burdened too.

Most changes in the children's lives occurred with fewer out-of-school activities due in part to the mothers' illness prohibiting them from being able to provide transportation for their children. Older children (age 15-17) felt that most of the changes in their lives due to

their mothers' illness revolved around friends. In general, both mothers and children reported that they felt burdened by the mothers' illness.

The development of innovative programs and practices for those with FM needs to include the many levels of the interdependent systems impacting the individual such as the family, community, and society. In addition, young caregivers need to be supported in their efforts to handle their dual roles – caregiver and student - and the related developmental tasks of positive peer relationships and identity development. Projects providing educational and social support, such as the Caregiving Youth Project of Pinellas, need to be implemented across the nation.

There is a huge vacancy in research on chronically ill parents, fibromyalgia, and parentification. It is hoped that this study will stimulate the interest of family research professionals. With longer life-spans and medical advances and increasingly more grandparents as primary caregivers for their grandchildren, more children, adolescents, and adults will be living with ill or disabled parents and grandparents. We need to be better informed about the impact of these conditions on the family system and the preventative and intervention strategies that need to be developed and implemented.

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Flyer - Seeking Mothers for Study

**SEEKING MOTHERS WITH
RHEUMATOID ARTHRITIS
AND/OR
FIBROMYALGIA**

Mothers are needed to participate in a new research study on how rheumatoid arthritis and/or fibromyalgia affects them and their families. This new research is being conducted by a University of New Mexico doctoral student in Family Studies. To participate in this study, you must be a woman between the ages of 25-57, have a child living with you between the ages of 11-17, and have been diagnosed with rheumatoid arthritis and/or fibromyalgia by a physician.

You and your child will be asked to provide 30 minutes of your time, at your convenience, to complete questionnaires.

To learn more about this study or to volunteer, you can contact Marie M. Duryea (researcher) at mduryea@unm.edu, call 1-505-XXX-YYYY, or return the attached post card.

Appendix B

Introductory Letter

Marie M. Duryea
Albuquerque, NM
(505) XXX-YYYY
e-mail: mduryea@unm.edu

Dear Rheumatology Patient,

My name is Marie Duryea and I am a doctoral student in Family Studies at the University of New Mexico and I am not employed by Lovelace Sandia Health Systems. This letter is to tell you about a research study I am doing. The purpose of this study is to find out how rheumatoid arthritis affects women and their families. Since you have rheumatoid arthritis, I wish to invite you to participate in this study.

Your rheumatologist has given you this letter because (s)he feels that you may be interested in taking part in this study. (S)he is not being compensated for her/his involvement. I am the only one who will know if you choose or decline to participate in this study and your health care will not be affected by your choice.

To be included in this study, you must be between the ages of 25-57 years, have a child living with you between the ages of 11-16 years, have been diagnosed with rheumatoid arthritis by a physician, and have had rheumatoid arthritis for at least one year.

If you meet these requirements and are interested in having you and your child participate or learn more about this study, please complete the attached post card - giving your name, your oldest child's name and age, your mailing address, phone number, and best time to call you. Please return the post card to me within 10 days. By returning the postcard, you are only agreeing to be contacted by me and you may decline any further participation or contact at any time.

I will contact you to answer your questions and to set up a convenient place and time for you to receive a packet of forms that include questions about your arthritis, general background information, and your feelings about how arthritis has affected you and your family. The questionnaires will take about an hour each for you and your child to complete. All answers will be completely private. You also will be asked to sign a consent form explaining the study, your guarantee of privacy, and the right to refuse or

withdraw from participating at any time with no penalty. After completing the surveys, both your name and that of the participating child will be entered into a drawing for \$50. This is a one-time only drawing and your odds are one to approximately 300.

Since your doctor is not involved in this research study, please contact me with any questions or concerns you may have at: Marie Duryea, 9512 Candle Lane NE, Albuquerque, NM, 87111, (505)-xxx-xxxx. You also may contact the Chair of my dissertation committee, Dr. Virginia Shipman, IFCE, Simpson Hall, MSC05 3040, 1 University, Albuquerque, NM 87131, (505) 277 - 4063. If you have other concerns or complaints, contact the Institutional Review Board at the University of New Mexico, Professor Jose Rivera, Scholes Hall, Room 255, Albuquerque, NM 87131, (505) 277 - 2257.

Please give serious thought to taking part in this study. Your participation will help us to better understand mothers with rheumatoid arthritis and how illness may affect their children. It is hoped that the information that you provide will suggest ways that health providers and family professionals can better help other women in similar situations.

Sincerely,

Marie M. Duryea

Appendix C

Post Card Enclosure

(Place on post card and enclose with introductory/recruitment letter)

If you are interested in participating or learning more about this study, please complete the following information and drop it in the mail. Thank you!

Your Name: _____

Your mailing address:

Your phone number: _____

Best days and times to call you:

Name of oldest child between ages 11-16 who is living at home with you: _____

Circle this child's age: 11 12 13 14 15 16 and sex: Male Female

Please drop this post card into the mail **within 10 days**. I will call you to discuss the study in more detail.

Thank you.

Appendix D

Telephone Contact

“Hello, may I speak with _____. Hi, my name is Marie Duryea and I am from the University of New Mexico’s Family Studies program. Awhile ago, you expressed an interest in having you and your child participate in a research study on mothers with rheumatoid arthritis and how it affects you and your family. I am calling today to ask if you would like to volunteer to participate in this study. (YES NO)
If NO, “Thank you for your time.”

If YES, “ Are you the parent or guardian of your oldest child who is living with you?”
(YES NO)

If NO, “May I speak to her/his parent/guardian to ask for consent for her/him to participate in this study if she/he is willing to do so?”

If NOT PARENT/GUARDIAN, “A parent consent form will need to be signed before s/he can complete the materials for the study. How would this best be done?”

If YES, “Will you allow her/him to participate, if she/he is willing to do so?” (YES NO)
If NO, “Thank you for your time.”

If YES, “This is great. Thank you! I need to read a short statement about the study to you. It will only take a minute. Any information that you or your child provides to me will be kept confidential and won’t be able to be traced back to either of you. You and your child may change your minds about participating at any time and may stop at any point while completing the surveys. It will take about one hour for each of you to complete the questionnaires. After completing the questionnaires, both of your names will be entered into a drawing for \$50.

I will provide a packet of materials to both you and your child. A copy of this statement is included in both packets as a Consent Form. Each of you will be asked to sign one.

May I deliver the packets of materials to you and child at your next rheumatologist appointment? (YES NO)

If YES, “Great! I’ll call you a few days before the appointment to set up where we can meet. In the meantime, if you have any questions or concerns feel free to call me at 505-828-0768. I would like to thank you for taking the time to talk to me today.”

If NO, “Would it be more convenient if I mailed the packets to you and _____?”

(YES NO)

If YES, “To what address should I mail these?”

Stamped and addressed envelopes will be included in the packets. After completing the questionnaires, please put them in the envelope and drop them in a mailbox.

If NO, “What is the best way I get these to you?”

If you have any further questions about this study, you may call me at 505-xxx-xxxx, my advisor, Dr. Virginia Shipman at 505-277-4063, or the Chair of the UNM Human Subjects Institutional Review Board, Dr. Jose Rivera at 505-277-2257.

I would like to thank you for taking the time to talk to me today.

“Is it possible to speak with your oldest child now? I would like to explain the study to him/her and see if (s)he has any questions.”

If NO, “When would be a convenient time to call him/her?”

If YES, “Hi _____. I am Marie Duryea and I have been talking to your mother about being in a study that I am doing on mothers with arthritis and how it affects them and their families. She thinks that you might like to be part of this study. Am I right?”

If NO, “Well, thank you for speaking with me today.”

If YES, “This is great! Let me tell you a bit about it. You will be given two questionnaires to fill out. They will take about 1 hour to complete. One questionnaire asks about some general background information such as your age, grade in school, work,

and leisure activities, as well as asking for your thoughts and feelings about your mother's illness. The second questionnaire asks about life in your family.”

“If you decide to take part in this study, please understand that participation is strictly voluntary. Refusing to take part in this study will not be held against you. You are free to stop at any time with no penalty to you, nor will it affect your mother's health care treatment. You may refuse to answer any particular question that you wish. There are no known harmful effects in participating.”

“The information you give will be used for research purposes only. No one, except me, will know how you answered the questions given to you. Any information that you give in connection with this study will remain confidential and will be disclosed only with your permission.”

“When both you and your mother have completed the questionnaires, each of your names will be entered into a \$50 drawing.”

“You will receive the packet of questionnaires soon. There will be two assent forms for you to sign. You are to keep one and return the other one with your answered questionnaires.”

“Do you have any questions for me? If you think of any questions or have any concerns feel free to call me at 505-XXX-YYYY. I would like to thank you for taking the time to talk to me today.”

Appendix E

Consent To Participate In Research

You have been asked to participate in a research study conducted by Marie Duryea, a doctoral student, from the Family Studies program at the University of New Mexico. This study is being done as part of the requirements for completion of my Ph.D. in Family Studies.

You were selected as a possible participant in this study because you have been diagnosed with rheumatoid arthritis for at least one year, are between the ages of 25-57, have a child age 11-17 living at home with you, and can physically complete the written questionnaires. Also, you have indicated an interest in being this study.

This is a research study of mothers with rheumatoid arthritis and the effects this may have on their children. Very little research has been done in this area. The goal of this study is to increase understanding of the relationship between mothers' chronic illness and the impact of this on their children.

You will be given one questionnaire which takes about 30 minutes to complete. The questionnaire contains sections on general background information, medical history, and impact of the illness. Your oldest child between the ages of 11-17 will receive two questionnaires to complete which also will take about 30 minutes. One questionnaire asks for some general background information such as your child's age, grade in school, work, and free-time activities, as well as asking for her/his thoughts and feelings about your illness. The second questionnaire asks about life in your family. When you are done with your questionnaire, please place it in the stamped and addressed return envelope and mail it back to me. You are asked to not discuss these questionnaires with anyone until they have been completed and mailed.

After completing the questionnaires, both your name and that of your participating child will be entered into a drawing for \$50. A one-time drawing will be held after information has been collected from all participants. The odds of winning are approximately one in 150.

Although there are no known harmful effects in participating, you may be asked some questions that deal with personal or emotional matters, such as illness related stress, tensions, moods or feelings, parent-child relationships in the family, positive and negative aspects of the illness, and the burden of the illness. You may refuse to answer any questions that you wish. A list of appropriate counseling agencies will be available if you feel a need to contact them to discuss these issues further.

Although I cannot guarantee that you will receive any direct benefits for participating in this study, your participation will help us to better understand mothers with rheumatoid arthritis and how illness may affect their children. It is hoped that the information you provide will suggest ways that health providers and family professionals can better help other women in similar situations. It also is hoped that the findings will encourage

further research on chronically ill mothers and their children and will benefit other mothers with rheumatoid arthritis.

Any information obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. The information you give will be used for research purposes only and will not go into your medical records. No one, except myself, will know how you personally answered the questions given to you. To assure confidentiality, all returned materials will be filed and stored in a locked file at my home.

You can choose whether to participate in this study or not. If you volunteer to participate, you may withdraw at any time without penalty or loss of benefits to which you might otherwise be entitled. Refusing to take part in or withdrawing from this study will not be held against you or affect your doctor/patient relationship or treatment. The investigator may withdraw you from this research if circumstances arise which warrant doing so. For example, information is needed from both you and your child for this study to take place. If one person decides to not participate, then the other person will be withdrawn from the study.

If you have any questions or concerns about the research, please feel free to contact me at: Marie Duryea, 9512 Candle Lane NE, Albuquerque, NM, 87111, (505)-XXX-YYYY. You also may contact the Chair of my dissertation committee, Dr. Virginia Shipman, IFCE, Simpson Hall, MSC05 3040, 1 University, Albuquerque, NM 87131, (505) 277 - 4063. If you have other concerns or complaints, contact the Institutional Review Board at the University of New Mexico, Professor Jose Rivera, Scholes Hall, Room 255, Albuquerque, NM 87131, (505) 277 - 2257.

SIGNATURE OF RESEARCH PARTICIPANT

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. Two copies of this form have been provided to me. I will keep one for my records and return the second copy with my questionnaire.

Name of Participant (please print)

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

In my judgment, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Signature of Investigator or Designee

Date

Appendix F

Assent To Participate In Research

My name is Marie Duryea, and I am a graduate student at UNM majoring in Family Studies. I am asking you to take part in a research study I am doing for my doctoral degree because I am trying to learn more about how having a mother with rheumatoid arthritis affects children and families.

If you agree to be in this study, you will be given two questionnaires to fill out. One questionnaire asks about some general background information such as your age, grade in school, work, and free-time activities, as well as asking for your thoughts and feelings about your mother's illness. The second questionnaire asks about life in your family. They will take about 30 minutes to do and then you are to mail them back to me in the envelope that comes with them. You are asked to not discuss these questionnaires with anyone until they have been completed and mailed.

After completing the questionnaires, both your name and that of your mother will be put into a drawing for \$50. A one-time only drawing will be held after the questionnaires have been collected from all the people taking part in this study. Your chances of winning will be about one in 150.

Some of the questions are personal and ask you about your feelings, how you deal with family responsibilities, and how your mother's illness may affect you. You do not have to answer any of the questions if you do not want to or if they make you feel too uncomfortable. If you feel like you need to talk to someone after answering these questionnaires, I can give you a list of places you can contact. No one, except me, will know how you answered the questions given to you.

Very little is known about how children are affected by their mother's illness. Taking part in this study will give doctors and family professionals new information on ways to help mothers with rheumatoid arthritis and their children.

Please talk this over with your mother before you decide whether or not to participate. I will also ask your mother to give her permission for you to take part in this study. But even if she says "yes", you can still decide not to do this. Remember, being in this study is up to you. No one will be upset if you don't want to participate or even if you change your mind later and want to stop.

You can ask any questions that you have about the study. If you have any questions later, you can e-mail me at: mduryea@unm.edu or call me at (505) XXX-YYYY or the chair of

my dissertation committee, Professor Virginia Shipman at (505) 277-4063.

Signing your name means that you agree to be in this study. After you have signed all three (3) forms, keep one copy for yourself, give one copy to your mother, and mail one copy back to me along with your two questionnaires. Thank you.

Name of Child/Youth (please print)

Signature of Child/Youth

Date

Signature of Investigator or Designee

Date

Appendix G

Code # A000

Mother's Questionnaire

Please print your name and today's date on the lines below.

First Name

Middle Initial

Last Name

Today's Date: _____

Questionnaire for Mothers

Directions: Please fill in the blanks or check the appropriate answer. This information will remain confidential and it will only be used to better understand the participants in this study. There are no right or wrong answers, so please answer each of these questions as honestly as possible. Please do not discuss the questions or your answers with anyone until you have mailed back the questionnaires. **Your answers are VERY important to this research study.**

Part I. Background Information

1. What is your age? _____ years

2. What is your ethnicity/race?
 - ___ a. African-American
 - ___ b. Anglo/Caucasian
 - ___ c. Asian or Pacific Islander
 - ___ d. Hispanic/Mexican American/Latina
 - ___ e. Native American Indian (Please specify tribe.) _____
 - ___ f. Other (Please specify.) _____

3. What is your current marital status?
 - ___ a. Single or never married
 - ___ b. Married or living with a partner
 - ___ c. Separated
 - ___ d. Divorced
 - ___ e. Widowed

4. What is the highest level of education you have completed?
 - ___ a. Less than seven years of school
 - ___ b. Grades seven through nine
 - ___ c. Grades ten through eleven
 - ___ d. High school graduate or GED certificate
 - ___ e. Post high school trade or vocational training
 - ___ f. Some college courses
 - ___ g. Two years of college and/or Associate's degree
 - ___ h. College graduate (bachelor's degree)
 - ___ i. Some post-graduate courses
 - ___ j. Master's degree
 - ___ k. Doctoral degree

5. What is your current work/employment situation?
- a. Full-time employment (35 or more hours per week)
 - b. Part-time employment
 - 1. Number of hours per week _____ hours
 - c. Unemployed
 - d. Retired
 - e. Other (Please explain.) _____

6. Your occupation is/was _____.

7. How many persons age 19 and older are living in your home? _____

Beginning with yourself, please list their sex, age, and relationship to you in the form below:

	<u>Adult's first name</u>	<u>Sex</u>	<u>Age</u>	<u>Relationship to you</u>
a.	<u>YOU</u>	<u>Female</u>	<u>?</u>	<u>self</u>
b.	_____	_____	_____	_____
c.	_____	_____	_____	_____
d.	_____	_____	_____	_____
e.	_____	_____	_____	_____
f.	_____	_____	_____	_____
g.	_____	_____	_____	_____

8. How many children under age 19 are living in your home? _____

Please list these children's ages (from oldest to youngest), sex, and relationship to you. If necessary, use additional space on back of page.

	<u>Age</u>	<u>Sex (Male or Female)</u>	<u>Relationship to you</u>
a.	_____ years	_____	_____
b.	_____ years	_____	_____
c.	_____ years	_____	_____
d.	_____ years	_____	_____
e.	_____ years	_____	_____
f.	_____ years	_____	_____

Part II. Medical History

1. I have the following illness(es):

- a. rheumatoid arthritis
- b. fibromyalgia
- c. both rheumatoid arthritis and fibromyalgia

2. At what age did you begin having rheumatoid arthritis symptoms? _____ years

I do not have rheumatoid arthritis.

3. At what age did you begin having fibromyalgia symptoms? _____ years

I do not have fibromyalgia.

4. At what age were you diagnosed as having rheumatoid arthritis? _____ years

I do not have rheumatoid arthritis.

5. At what age were you diagnosed as having fibromyalgia? _____ years

I do not have fibromyalgia.

6. Did a rheumatologist diagnose your rheumatoid arthritis?

- a. Yes
- b. No Who gave you a diagnosis of rheumatoid arthritis? _____

7. Did a rheumatologist diagnose your fibromyalgia?

- a. Yes
- b. No Who gave you a diagnosis of fibromyalgia? _____

8. What parts of the body does your illness mainly affect?

9. What symptoms do you have?

10. In general, how severe are your symptoms?

- a. Not severe at all
- b. Only slightly severe
- c. Somewhat severe
- d. Very severe
- e. Extremely severe

11. During the past month, how often have you had these symptoms?

- a. Not at all
- b. A few days
- c. Once a week
- d. 2-6 days a week
- e. Every day

12. Do your symptoms appear as flare ups and remissions?

- a. No
- b. Yes
 1. About how often do you experience these flare ups? _____
 2. How long do the flare ups usually last? _____
 3. When was your last flare up? _____ (month/year)

13. Does treatment of your illness change during flare ups?

- a. No
- b. Yes In what ways?

Part III. Impact of Illness

1. How burdened do you feel by your illness?

- a. Not burdened at all
- b. Only slightly burdened
- c. Somewhat burdened
- d. Very burdened
- e. Extremely burdened

2. When you are having a flare up or difficulties due to your illness, who provides support or assistance to you? (Check all that apply.) How often do you receive support or assistance from each source you checked? **1 - never, 2- rarely, 3 - sometimes, 4 - most of the time, 5 - always** If you need more space, please continue on back of page.

Source of Support	Frequency (1-5)
<input type="checkbox"/> a. Husband/Partner	a. _____
<input type="checkbox"/> b. Child in study	b. _____
<input type="checkbox"/> c. Other children in home	c. _____

<u>Source of Support</u>	<u>Frequency (1-5)</u>
___ d. Other household member(s). List relationship to you:	
d ₁ . _____	d ₁ . _____
d ₂ . _____	d ₂ . _____
d ₃ . _____	d ₃ . _____
___ e. Other family members(s) not living in household. List relationship to you:	
e ₁ . _____	e ₁ . _____
e ₂ . _____	e ₂ . _____
e ₃ . _____	e ₃ . _____
___ f. Friend(s)	f. _____
___ g. Healthcare providers	g. _____
___ h. Clergy/other adults from place of worship	h. _____
___ i. Others. List relationship to you:	
i ₁ . _____	i ₁ . _____
i ₂ . _____	i ₂ . _____
___ j. No one	

3. How satisfied are you with the support and/or assistance you receive?

- ___ a. Very dissatisfied
- ___ b. Generally dissatisfied
- ___ c. Somewhat dissatisfied
- ___ d. Somewhat satisfied
- ___ e. Generally satisfied
- ___ f. Very satisfied

Part IV. Parent/Child Relations

1. In general, how close a relationship do you have with the child in this study?

- ___ a. Not close at all
- ___ b. Only slightly close at times
- ___ c. Somewhat close
- ___ d. Very close
- ___ d. Extremely close

2. During the teenage years, there are often many changes in parent-child relationships.

During the past year, what changes have you experienced in your relationship with the child in this study?

3. When a mother is ill, there can be both positive and negative ways that relationships can be affected.

3a. Do you think that your illness has affected your relationship with the child in this study in any positive or good ways?

1. No

2. Yes In what ways?

3b. Do you think that your illness has affected your relationship with the child in this study in any negative or troublesome ways?

1. No

2. Yes In what ways?

4. How bothered or burdened do you feel the child in this study is by your illness?

a. Not bothered or burdened at all

b. Only slightly bothered or burdened

c. Somewhat bothered or burdened

d. Very bothered or burdened

e. Extremely bothered or burdened

5. Children usually change with development and with new friends, etc. Since your illness, have there been changes for the child in this study in any of the following areas? If you answer YES to any of the questions, explain how it has changed and to what extent, if any, you think the changes are due to your illness. **1 - not at all, 2- only a little bit, 3 - somewhat, 4 - a lot, 5 - very much so** If necessary, use additional space on back of page.

a. School Grades

1. No

2. Yes In what ways?

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

b. School Attendance

1. No

2. Yes In what ways?

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

c. School Activities

1. No
 2. Yes In what ways?
-

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

d. Friends

1. No
 2. Yes In what ways?
-

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

e. Activities outside of school

1. No
 2. Yes In what ways?
-

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

f. Hobbies

1. No
 2. Yes In what ways?
-

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

g. Other ways?

1. No
 2. Yes (Please describe.)
-

A. Extent due to illness? _____ (1, 2, 3, 4 or 5)

6. Are there any family responsibilities and duties the child in this study usually performs?

- a. No
 b. Yes (Please list what they are.)
-
-
-
-

7. During flare ups in your illness, does he/she do additional things for you or the family?

a. No

b. Yes (Please list what these are.)

8. People with illnesses often experience stress. In the past year, have you experienced stresses due to your rheumatoid arthritis and/or fibromyalgia?

a. No

b. Yes What were they?

9. Does the child in this study have any health problems?

a. No

b. Yes (Please list them.)

10. While you were growing up, were either of your parents chronically ill or unable to do things around the home and/or with the family?

a. No

b. Yes Did your responsibilities or duties change at such times?

1. No

2. Yes In what ways?

Appendix H

Code # Y000

Youth's Questionnaire

Please print your name and today's date on the lines below.

First Name	Middle Initial	Last Name
------------	----------------	-----------

Today's Date: _____

Questionnaire for Youth

Directions: Please fill in the blanks or check the appropriate answers. This information will remain confidential and it will only be used to better understand the participants in this study. There are no right or wrong answers, so please answer each of these questions as honestly as possible. Please do not discuss the questions or your answers with anyone until you have mailed back the questionnaires. Your answers are VERY important to this research study!

Part I. Background Information

1. What is your age? _____ years

2. What is your sex?
 - ___ a. Male
 - ___ b. Female

3. What is your ethnicity/race?
 - ___ a. African-American
 - ___ b. Anglo/Caucasian
 - ___ c. Asian or Pacific Islander
 - ___ d. Hispanic/Mexican American/Latina
 - ___ e. Native American Indian
 - ___ f. Other (Please specify.) _____

4. What grade are you in school? _____

5. What is your current job situation?
 - ___ a. Not working
 - ___ b. Working
 1. What do you do?

 2. What is the average number of hours you work per week? _____ hours

6. During the school year, how many hours a week do you spend in free-time activities outside of home and the regular school day? _____ hours

7. Please list the three (3) ways you spend most of your free time.
 1. _____
 2. _____
 3. _____

Part II. Impact of Illness

1. Which of the following illnesses does your mother have:

- a. rheumatoid arthritis
- b. fibromyalgia
- c. both rheumatoid arthritis and fibromyalgia

2. How bothered do you feel by your mother's illness?

- a. Extremely bothered
- b. Very bothered
- c. Somewhat bothered
- d. Only slightly bothered
- e. Not bothered at all

3. When your mother is having a flare up of her illness, do you receive support or help from anyone?

- 1. No
 - 2. Yes (Check all that apply.)
 - a. Mother
 - b. Father
 - c. Step or adoptive parent
 - d. Brother(s)
 - e. Sister(s)
 - f. Other family member(s)
 - 1. How are they related to you? _____
 - g. Special boyfriend or girlfriend
 - h. Other friend(s)
 - i. Teachers/Coaches
 - j. School counselors
 - k. Clergyman or other adults from your place of worship
 - l. Others (Please describe their relationship to you.)
-
-

4. How satisfied are you with the support and/or assistance you receive?

- a. Very dissatisfied
- b. Mostly dissatisfied
- c. Somewhat dissatisfied
- d. Somewhat satisfied
- e. Mostly satisfied
- f. Very satisfied

5. How close do you feel you and your mother are?

- a. Extremely close
 b. Very close
 c. Somewhat close
 d. Only slightly close
 e. Not close at all

6. During the teenage years, there often are many changes in relationships. In the past year, what changes have you experienced in your relationship with your mother?

7. When mothers are ill, there can be both good and bad effects on the family.

7a. Do you think your mother's illness has affected you in any good (positive) ways?

1. No
 2. Yes If so, in what ways?

7b. Do you think your mother's illness has affected you in any bad (negative) or troublesome ways?

1. No
 2. Yes If so, in what ways?

8. Have any of the following things changed since your mother became ill with rheumatoid arthritis and/or fibromyalgia? If you answer YES to any of the questions, explain how it has changed. If you need more space, please use the back of this page.

a. School Grades

1. No
 2. Yes In what ways?

b. School Attendance

1. No
 2. Yes In what ways?

c. School Activities

- 1. No
- 2. Yes In what ways?

d. Friends

- 1. No
- 2. Yes In what ways?

e. Activities outside of school

- 1. No
- 2. Yes In what ways?

f. Hobbies

- 1. No
- 2. Yes In what ways?

g. Other ways?

- 1. No
- 2. Yes (Please describe.)

9. Please list the responsibilities, chores, and duties you have in the family. If you need more space, please use the back of this page.

10. During flare ups of your mother's illness, do you do any additional things for her or other family members?

- a. No
- b. Yes (Please list these additional responsibilities and/or duties.)

11. It is common for people of all ages to experience stress from such things as worries, fears, relationships with friends, and/or pressure from peers, family members, teachers, school, job, etc.

11a. What stresses have you experienced during the past year?

11b. What stresses due to your mother's illness have you experienced during the past year?

11c. How do you usually handle any stress you experience?

12. Do you have any health problems?

- a. No
- b. Yes (Please list them.)

I really would like to hear any additional concerns, information, or comments that you may have. These can be written here.

THANK YOU very much for your help by completing this questionnaire!

Appendix I

Mother's Packet Instructions

Dear _____,

Thank you for contacting me.

Here is the questionnaire to be completed by you for the study on mothers with rheumatoid arthritis and/or fibromyalgia and the effects on them and their children.

This questionnaire has three sections. The first section provides needed information to help describe in general the people who took part in the study, what their families are like, and their general health. The second section provides information about your rheumatoid arthritis and/or fibromyalgia, the symptoms, flare-ups, and treatment. The third section provides information on the impact of rheumatoid arthritis and/or fibromyalgia on you and your child.

Take your time to complete this questionnaire. There are no right or wrong answers. Just answer honestly based on how you feel or what you believe. If you wish to discuss your answers with others, please do so only after you have mailed the questionnaire back.

When you are done, **three** items should be returned to me. Please put the **one (1) survey, one (1) copy of your signed Consent Form, and one (1) copy of the Parent/Legal Guardian form** in the return envelope and mail it to me. Thank you!

I appreciate the time you have spent in helping me with this very important research. Once I receive the completed questionnaires, your name and that of your child will be entered into a one-time drawing for \$50. Your chances of winning are about 1 in 150.

Thank you,

Marie M. Duryea

Appendix J

Parent/Legal Guardian Consent for Research

I, the undersigned, am the parent or legal guardian of _____ and I agree to have him/her participate in a research project on mothers with rheumatoid arthritis and the effects of it on them and their children. This study is being conducted by Marie M. Duryea, a doctoral student from the Family Studies Program at the University of New Mexico. As part of this project, my child will independently complete two questionnaires that will take approximately 1 hour of his/her time.

My child has volunteered to participate in this study and realizes there will be no penalty for withdrawing at any time. All information will be held in the strictest confidence. Two copies of this form have been provided to me. I will keep one for my records and return the second copy with my two questionnaires.

Date: _____ Signature of Parent/Guardian: _____

Date: _____ Signature of Researcher: _____

Appendix K

Notification of Study Results

If you choose to participate and would like the results of this study, please provide the following information so I can contact you when the report is completed:

I wish to receive a copy of the results of this study.

Name: _____

Address: _____

Please mail this page back to me with your completed questionnaire(s).

Thank you!

Appendix L

Youth Packet Instructions

Dear _____,

Here are your questionnaires to be completed for the study on mothers with rheumatoid arthritis and/or fibromyalgia and their children. There are two (2) questionnaires that you are to complete:

- 1). Youth's Questionnaire - The first section provides needed information to describe the people who took part in the study, the ways you spend your free time, and your job situation. The second section provides information about your relationship with your mother and the effect of your mother's disease(s) on you.

- 2) Family Life Questionnaire - Youth - This questionnaire describes some of the things that may be going on in your life right now, especially in your family.

Take your time to complete these questionnaires. There are no right or wrong answers. Just answer honestly based on how you feel or what you believe.

When you are done, **three** items should be returned to me. Please put in the enclosed return envelope the **two (2) questionnaires and one (1) signed Assent Forms** and mail it to me. Please don't discuss the questions or your answers with others until the questionnaires are mailed. Thank you!

I appreciate the time you have spent in helping me with this very important research. Once I receive the completed questionnaires from you and your mother, both of your names will be entered into a one-time drawing for \$50. Your chances of winning are about 1 to 150.

Thank you,

Marie M. Duryea

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