THE DEVELOPMENT OF THE NORMALIZATION ASSESSMENT MEASURE

By

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I dedicate this dissertation:

To my mother and father for encouraging me to dream, for fostering a strong foundation to pursue the dream, and for loving and supporting me to reach the dream

To my husband, Dan, for his unquestioning devotion and support while I dreamed

To my son, Christopher, who I will love to infinity and beyond

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CHAPTER I

INTRODUCTION

Chronic Illness

Currently, scientific advances in the diagnosis and treatment of chronic illnesses have resulted in a society where individuals live longer and manage complex diseases on a daily basis. Diseases are considered to be chronic when there is an incurable, altered health state that requires long term management and treatment in order to prevent pathological progression and to preserve function (Lubkin, 1998; Sidell, 1997). The impact of chronic illness is significant for individuals, families, and communities. In fact, more than 25 million people must cope with chronic conditions. Financially, chronic diseases account for 75% of the nation's total health care costs (National Center for Chronic Disease Prevention and Health Promotion, 2002).

In addition to high financial costs, chronic illness results in unpredictable and potentially stigmatizing physical and psychological consequences. These consequences are often disruptive to the pursuit of daily activities. In stigmatization, individuals who appear or behave outside the expected range of normal are attributed to have less value by others (Goffman, 1963). Due to illness or treatment effects, individuals with chronic illness may appear to others to be outside the expected norms either physically or behaviorally. Individuals and families often cope with this potential stigmatization by minimizing the illness’s impact upon life activities and living as normally as possible. This coping process is termed normalization (Knafl & Deatrick, 1986; Miles, 1979; Robinson, 1993; Strauss et al., 1984).

Normalization

Normalization is defined as one way of adapting to chronic illness, and is comprised of several coping strategies that enable individuals and families to maintain typical life patterns (as defined by the individual or family) while acknowledging the presence and significance of the illness (Hilton, 1996; Knafl & Deatrick, 1986; Miles, 1979; Robinson, 1993; Strauss et al., 1984). Coping strategies are cognitive and behavioral tactics used by individuals when demands are appraised as stressing the resources of the person (Lazarus & Folkman, 1984). Through these coping efforts, individuals can change the stressful situation, alter the meaning of the stressful situation, or control their reaction to the stressful situation (Jones, 1991).

Problem Statement

To date, research findings have associated normalization with the following outcomes: (1) both a positive and negative quality of life (Anderson & Chung, 1982; Robinson, 1993; Wiener, 1975); (2) both compliance and noncompliance with treatment regimens (Anderson, 1986; Deatrick, Knafl & Murphy-Moore, 1999; Gerhardt & Brieskorn-Zinke, 1986; Jerrett & Costello, 1996, Miles 1979; Rehm & Franck, 2000); (3) increased and decreased resource utilization (Hilton, 1996; Miles, 1979; Robinson, 1993, Royer, 1995); and (4) maintenance of social ties (Dewis, 1989; Rehm & Franck, 2000).

Normalization research has been predominantly qualitative. Currently, there is no measurement instrument for normalization. The contradictory outcomes associated with normalization necessitate further investigation, particularly quantitatively. The concept of normalization requires further refinement with both qualitative and quantitative research, but the lack of a normalization measure is a problem if one is to pursue this phenomenon quantitatively.

Purpose

The purpose of this study was to refine the concept of normalization by developing a normalization measure and to ascertain the psychometric properties of the instrument using a sample of individuals diagnosed with rheumatogical conditions.

Significance

The prevalence of chronic illness and its associated cost in terms of financial loss, loss of productivity, and emotional tolls supports the premise that understanding how patients cope with chronic illness should be a research priority (O’Brien, 1993). Nursing professionals have a unique role in facilitating the transitions associated with chronic illness (Deatrick et al., 1999; Meleis, 1997; Robinson, 1993). In numerous settings, nurses have direct contact with individuals and families experiencing chronic illness. This gives nurses the opportunity to assess individual and family coping. In fact, normalization has been used as a way for health professionals to evaluate an individual's or family's effectiveness in managing chronic illness.

In families experiencing difficulty coping with chronic illness, the promotion of normalization has been recommended (Knafl, Deatrick & Kirby, in press). The Nursing Intervention Classification system (NIC) identifies the promotion of normalization as a nursing intervention, which supports the notion that normalization is both "positive" and significant to nursing (McCloskey & Bulchek, 2000). Nurses' promotion of normalization can be integrated as a nursing function in the context of Orem's (1995) theory of self-care agency. Chronically ill individuals experience the need for normalcy and seek a lifestyle that promotes continued personal development. Nursing's role, in Orem's view, is to meet these self-care requisites that the individual cannot meet alone and to foster self-care agency.

The continued development and refinement of the normalization construct is warranted because the circumstances of normalization with positive outcomes and for whom normalization is beneficial remains to be identified. Quantifying this concept will provide a foundation for exploring the specific relationships between influencing variables and normalization, thus building more nursing knowledge on this topic. With greater knowledge, nurses will intervene more appropriately with chronically ill individuals and families. Expected outcomes include better management of the chronic condition, increased health status, and minimal detrimental effects on typical life patterns (Knafl et al., in press).

Normalization research is significant to nursing because nurses need to know when to promote normalization, how best to promote normalization, and how to recognize the consequences of normalization. Quantitative research provides a way to describe specific relationships among variables and to predict outcomes. The answers to the following questions would enhance our understanding of normalization. What personal characteristics lead to successful normalization? What specific circumstances (such as family life stage, disease severity) lead to successful normalization? What individual characteristics and specific circumstances in the midst of normalization lead to positive outcomes? These questions are best answered by quantitative research; thus a normalization measure is necessary.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

In order to develop a measure of normalization, there must be clarity about the construct to be measured (DeVellis, 1991). For the term normalization, there are several different definitions reflected in the literature (see Table 1 on the next page for a comparison of definitions). While several conceptualizations exist, two conceptual analyses have resulted in a primary definition. This primary definition was used to guide this study. The following discussion will describe the historical background of the definitions and then will present the most recent definition that is used in this study.

Theory can be utilized to guide scale development. In addition to clarity about the construct, theory can be a source of information for the design of items to be included in the scale (DeVellis, 1991). Previous research has resulted in agreement about the cognitive and behavioral strategies used in normalization. This area of agreement helps to establish clarity about the construct. Additionally, the literature supports several consistent elements of the normalization definition. In addition to exploring the definitions of normalization, the following discussion will also present information about the cognitive and behavioral strategies, antecedents, influences and outcomes of normalization, as well as the proposed conceptual framework.

Table 1: Historical Development of Normalization Definitions

Author/ Year	Concept	Definition	Defining Characteristics
Schwartz (1957)	Normalcy Framework	Deviant behaviors are converted into a reasonable perception	1. Acknowledge deviance 2. Rationalizing behaviors as normal 3. Family perspective of normal 4. Identity focus
Davis (1961)	Deviance Disavowal	A 3-stage process where the individual rejects deviance and is embraced as normal by others	1. Process approach 2. Cognitive emphasis 3. Identity focus 4. Normal defined by social interaction 5. Fictional acceptance 6. Facilitation of reciprocal normalized role taking 7. Institutionalization of the normalized relationship
Goffman (1963)	Normalization	Refers to normal individuals treating a stigmatized person as normal	1. Emphasis on others' perceptions 2. Emphasis on the behavior of others
Wolfens-berger (1972)	Normalization	Providing an environment which is as culturally normal as possible in order to establish or maintain personal behaviors and characteristics viewed by the culture as normal	1. Multi-level 2. Viewed as a meta theory 3. Normal is culturally defined 4. Environmental emphasis 5. Process and goal oriented 6. Human management applications
Knafl & Deatrick (1986)	Normalization	A cognitive and behavioral adaptation process involving the use of coping techniques which minimize the impact of disease, enable the individual to engage in normal activities and result in the manifestation of a normal appearance to others	1. Acknowledge the impairment presence 2. Define life as basically normal 3. Illness social consequences minimized 4. Engage in behavior that demonstrate normalcy to others 5. Individual and family perspective 6. Identity focus 7. Process & goal oriented 8. Cognitive & behavioral
Deatrick et al. (1999)	Normalization	Same as (1986)	1. Acknowledge impairment & seriousness 2. Define family from a normalcy lens 3. Engage in parenting and family routines consistent with the normalcy lens 4. Incorporation of treatment regimens using normalcy lens 5. View child and family as normal in interactions with others
Morse et al. (2000)	Normalization	Identification with or adoption of norms of a targeted reference group	1. Self-identity focus 2. Group may not be normal others 3. Comparison focus

Definitions

History. The normalization construct has evolved significantly over time. The term normalization first appeared in the sociological literature with the seminal works of Schwartz (1957) and Davis (1961). Initially, normalization was conceptualized as a cognitive strategy to explain others' deviant behavior as normal (Schwartz, 1957). Schwartz (1957) had observed that wives of psychotic husbands often found ways to explain their husbands' behavior in a way that was consistent with the socially acceptable or normal range of behavior. Schwartz identified that these wives were operating from a "normalcy framework".

This "normalcy framework" was subsequently applied to the cognitive appraisal of the deviant individuals themselves. Davis (1961) used the term "deviance disavowal" to describe this phenomenon. The concept was viewed as a redefinition of self-attributes where visibly handicapped individuals rejected their deviance and projected themselves in such a way as to be viewed as normal by others, hence "normalizing" the otherwise deviant individual. The visibly handicapped perceived themselves as normal and similar to non-handicapped individuals. In 1963, Davis expanded the use of this cognitive construct when he described behavioral as well as cognitive strategies used by a sample of polio patients. In addition to identifying behavioral aspects of this concept, this research brought the concept into the chronic illness realm.

Alternatively, Goffman (1963) used the term normalization to refer to the treatment of deviant individuals by normal individuals. Goffman differentiates “normification” from “normalization.” An individual who presents himself as normally as possible exemplifies normification, according to Goffman. Normalization refers to normal individuals treating a stigmatized person as normal. Except for recent research by Scherman, Dahlgren, & Lowhagen (2002), the chronic illness literature consistently uses the term “normalization” for both connotations. Scherman et al. (2002) identify normalization consistent with Schwartz’s (1957) normalcy framework. Normalization is the interpretation of illness symptoms as normal. The conceptualization of normification in this work is consistent with Goffman (1963). Using the historical definition of normalization reflects a failure to acknowledge the evolution of the concept. For the purposes of this study, the term normalization was utilized instead of normification. This is consistent with the predominant use of the term in the overall literature.

In the human management area, the concept of normalization became a popular focus for care of the mentally retarded. The concept of allowing the mentally retarded to live as normally as possible was written into Danish law in 1959. In 1969, the Swedish government adopted the Danish philosophy, and the concept of normalization began to appear in Scandinavian literature. The reformulation of the concept occurred with the writings of Wolfensberger (1972) who defined normalization as the “utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” (p. 28). He described the term “normative” as synonymous with “typical” and explored normalization both as a process and as a goal. In this literature, normalization is considered a human management approach and is often an administrative strategy. Because of this, normalization is referred to as a principle.

Wolfensberger (1972) formulated the implications of normalization as two-dimensional with three levels of action. See Table 2 on the next page for a summary of these levels. In contrast to the identity and self-defining approaches of Schwartz (1957) and Davis (1961, 1963), Wolfensberger's conceptualization focuses on the perceptions of others and the manipulation of the environment to elicit or maintain behavior viewed by the culture as normal. In this conceptualization, normalization is not a coping strategy but a management approach. Wolfensberger's conceptualization of normalization currently is viewed as the use of "cultural means that establish, enable and support behaviors, appearance, experiences and interpretations which are as culturally normative as possible" for those individuals who may be devalued in society (Wolfensberger, 1977). Cultural means have resulted in deinstitutionalization and mainstreaming tactics.

Other definitions include those by Wiener (1975) and Gerhardt & Brieskorn-Zinke (1986). Wiener (1975) defined normalization as any behavioral attempt used in order to maintain a normal life and categorized normalization by the use of three strategies: covering-up; keeping-up; and pacing. She emphasized that activities are engaged in as if normal despite physiologic priorities. This definition is strictly behavioral and, thus, lacks the cognitive element of normalization. On the other hand, Gerhardt & Brieskorn-Zinke (1986) surmise that normalization is a process of attempted mastery of treatment regimens through routinization. This definition consists of both cognitive and behavioral aspects.

Table 2: Normalization on Three Levels of Two Dimensions of Action (Wolfensberger, 1972, p.32)

Levels of Action Dimensions of Action

	Interaction	Interpretation
Person	Eliciting, shaping, and maintaining normative skills and habits in persons by means of direct physical and social interaction with them	Presenting, managing, addressing, labeling, and interpreting individual persons in a manner emphasizing their similarities to rather than differences from others
Primary and intermediate social systems	Eliciting, shaping and maintaining normative skills and habits in persons by working indirectly through their primary and intermediate social systems, such as family, classroom, school, work setting, service agency and neighborhood	Shaping, presenting and interpreting intermediate social systems surrounding a person or consisting of target persons so that these systems as well as the persons in them are perceived as culturally normative as possible
Societal systems	Eliciting, shaping, and maintaining normative behavior in persons by appropriate shaping of large societal social systems, and structures such as entire school systems, laws, and government	Shaping cultural values, attitudes, and stereotypes so as to elicit maximal feasible cultural acceptance of differences

Recent Conceptualization. Consistent with the early work of Davis, successful normalization currently is viewed by nursing and in the health related literature as both a cognitive and behavioral process. Researchers subsequent to Davis have continued to examine normalization of individuals and families experiencing chronic illness, and to build on the dimensions of the process (Knafl, et al., in press). Knafl and Deatrick (1986), in a conceptual analysis of normalization, identified four key elements exhibited by individuals using this process.

The elements identified by Knafl and Deatrick included: (a) acknowledging that the impairment is present; (b) defining life as basically normal; (c) minimizing the social consequences of the illness; and (d) engaging in behavior that demonstrates normalcy to others. In other words, an individual or family who normalizes accepts that there is a deviation from health, but strives to live as usually as possible in spite of these limitations. To the extent that parents want to demonstrate the normalcy of their child, they may seek out experiences and situations to emphasize that normalcy. Parents may manipulate the environment and place their children in normal situations, similar to Wolfensberger's conceptualization of normalization. Subsequently, Deatrick et al. (1999) revised the key elements to include a fifth element: (e) the incorporation of treatment regimens consistent with normalcy. These may or may not be in compliance with the recommended treatment regimen.

Recently, consistent with the self-identity focus of normalization, Morse, Wilson, & Penrod (2000) suggested, "normalization is the identification with or adoption of the norms of a reference group." The emphasis in this definition is the comparison and identification of the self with others. Rather than assuming that the group of reference is "normal" others, Morse et al. (2000) proposed that individuals identify the targeted reference group and then seek to enhance their similarities and de-emphasize their differences to the targeted reference group.

There may be a fit between Morse et al.'s (2000) and Knafl & Deatrick's (1986) conceptualizations of normalization. One element from Knafl & Deatrick's (1986) definition is that the individual defines life as basically normal while another element is that individuals engage in behavior that demonstrates normalcy to others. One's definition of normal and the group to whom normalcy is demonstrated may depend on the targeted reference group as described by Morse et al. (2000).

There are authors who use the term "normalization" to indicate approximation of a behavior to the norm rather than using either of the identified conceptualizations of Deatrick et al. (1999) or Wolfensberger (1977). For instance, Haase & Rostad (1994) used the term "normalizing" in the context of children normalizing family relationships after completion of cancer therapy. This use of the term, while representing a return to normal or as normal as possible, doesn't fit (as described in their article) with all of the elements described by Knafl & Deatrick (1986) or Wolfensberger (1972). It may be that, with more information, the given example fits the normalization criteria delineated by Knafl & Deatrick (1986). However, Haase and Rostad did not reference a framework for normalization. As another example, Witte & de Ridder (1999) refer to normalization of feelings. This use of the term refers to more of a "validation" of feelings. This differs from the construct of normalization as discussed in this paper. Application of the term "normalization," as in these examples, does not contribute to the development of the construct.

Study Definition. The definitions proposed by Knafl & Deatrick (1986) and Deatrick et al. (1999) served as the primary conceptualizations for this research and for the developed normalization measure. This definition is consistent with recent works about normalization. Consonant with Knafl & Deatrick's work, normalization was conceptualized as an adaptation process consisting of the use of cognitive and behavioral coping strategies employed to minimize the impact of illness and maintain typical life activities. Adaptation has been conceptualized in a variety of ways, and, similar to normalization, has been viewed as both a process and outcome (Kim & Kollak, 1999). For this proposal, adaptation is defined as the outcome of an individual's adjustment to the environment through complex cognitive, emotional, physiological, and behavioral interactions over time (Pitel, 1963; Scott, Oberst & Dropkin, 1980).

Normalization is an adaptation process resulting in the preservation of normalcy, social interaction, and self-identification with others. Normalization is one mode of adaptation. Individuals may choose other modes of adaptation not involving the desire for normalcy. For instance, an individual may adapt to illness by surrendering to the sick body as described by Charmaz (1995). Through surrendering, the individual no longer struggles against the illness, doesn't redefine the illness, and accepts the progressing disease. This is supported by Gagliardi (1991) who described the resolution process experienced by families who have a child with Duchenne's muscular dystrophy. The families experienced disillusionment with the world when faced with the impossibility of a normal life. The families worked through the disease, accepted physical changes, and reached resolution through accepting the disability. This is a process of adaptation, different from normalization. Thus, adaptation and normalization are not one and the same. Normalization is one mode of adaptation.

Normalization is a dynamic process occurring over time in which there is a continuous interaction between what is perceived to be normal by the identified unit (individual, couple, or family) and what characteristics of normal can be attained or maintained, thereby shaping the perceptions of others. Of particular importance is the premise that the individual, couple, or family defines normalization. The definition of normal held by others (specifically health professionals) may not match with the individual’s self-perception or own definition. For example, Robinson (1993) described a woman who wanted a wheelchair so she could go shopping. Her sense of going shopping as a usual activity was more important to her than appearing physically normal to others. There are temporal aspects to normalization, perceptual (or cognitive) aspects to normalization, and behavioral aspects to normalization, thus creating a dynamic, cognitive-behavioral process.

Attributes

Universality. Research about normalization has illustrated the universality of the concept. Normalization is evident among persons coping with a chronic illness regardless of the disease type. Research has identified normalization as a dominant mode of adaptation among individuals and/or families experiencing the following conditions: AIDS; amputation; arthritis; asthma; cancer; cerebral palsy; coronary artery bypass graft; cystic fibrosis; diabetes; Duchene’s muscular dystrophy; dwarfism; end-stage renal failure; gastrostomy; heart transplantation; HIV positive; inflammatory bowel disease; leukemia; low birth weight infants in an ICU setting; lung transplantation; multiple sclerosis; myelomeningocele; osteogenesis imperfecta; physical disability; post-polio syndrome; precocious puberty; Retts syndrome; spina bifida; spinal cord injury; and Turner’s syndrome (see Appendix A for a summary of the research).

While normalization has been identified across chronic illnesses, it is unclear whether normalization is a universal concept culturally. The research to date on normalization has focused primarily on American and European Caucasian individuals. Anderson (1986) proposed that normalization might be a western ideal. In a study of Chinese families living in Canada, Anderson (1986) identified that, in these families, concern for the future of the chronically ill child is the focus of concern, not the maintenance of normal. These families viewed their children as not normal and did not treat the children as if they were normal but emphasized the child’s happiness. Later Anderson (1989) acknowledged that the material circumstances for Chinese immigrants in Canada rather than simply their cultural background might complicate and influence the ways that they cope with a chronically ill child. In any case, it appears that normalization may not be universal within all sociocultural contexts.

Cognitive and Behavioral Strategies of Normalization. Cognitive and behavioral strategies are attributes of normalization. Behavioral strategies of normalization consist of ways in which chronically ill persons carry on life as usual or engage in activities similar to their pre-diagnosis life. Additionally, extraordinary efforts are made to maintain a normal appearance. For example, chronically ill individuals may hide their physical pain (Wiener, 1975). Chronically ill individuals may pace themselves and may choose to skip ‘trivial’ activities in order to maintain participation in more valued activities (Royer, 1995; Wiener, 1975). Avoiding potentially embarrassing situations related to physical aspects of their illness is another behavioral strategy. For example, one woman doesn't shop when her hands are swollen because she feels people will look at her (Royer, 1995). Limiting contact to persons who are in similar circumstances is a behavioral tactic. People who socialize with others similar to themselves may find understanding and respect for their situation. Another behavioral strategy is covering up. In this strategy, individuals attempt to maintain a normal appearance to others. For example, an individual using this strategy would be loath to use assistive devices such as canes or might not take medication in public (Dewis, 1989; Guthrie & Castelnuovo, 2001; Hilton, 1996; Wiener, 1975; Robinson, 1993; Royer, 1995).

Cognitive strategies are also a part of the normalization process. Cognitive strategies include minimizing the struggles and adjustment that affect an ill individual's life. This might be accomplished by viewing the illness as common or inconsequential within their life (Knafl & Deatrick 1986; Robinson, 1993; Hilton, 1996, Royer, 1995) or by minimizing the role of treatment regimens in their daily routine (Deatrick et al., 1999; Royer, 1995). A way to minimize the role of treatment regimens is to view treatment as a part of staying healthy, similar to brushing one's teeth every day (Rehm & Franck, 2000). Other cognitive strategies include being flexible (Hilton, 1996) and being able to balance demands (Wiener, 1975). Normalizing individuals frequently frame their situation in an optimistic manner. Statements such as "it could be worse" or "the glass is half full rather than half empty" are examples of this optimistic view (Hilton, 1996; Royer, 1995). The strategy of redefining normal to be consistent with the present level of functioning also results in individuals being able to maintain normalcy (Wiener, 1975, Royer, 1995). This often requires a reordering of priorities and values based upon the level of functioning.

Often cognitive and behavioral strategies are intertwined. Individuals may seek out information that validates their personal experience from support groups or other avenues of gaining information (Miles, 1979; Royer, 1995). However, some individuals may view their handling of the illness as superior to other individuals with the same illness. Once the individuals obtain the needed information, they no longer attend meetings. On the other hand, they may actually seek out individuals who have similar diagnoses to them but are worse off in their ability to manage the illness (Royer, 1995). This is called making a downward social comparison (Festinger, 1954).

These are some of the behavioral and cognitive normalization strategies utilized by chronically ill individuals. Individuals may use a variety of these strategies but do not need to employ all of these tactics in order to be normalizing. These strategies yield information about the types of items to include on the proposed scale of normalization.

Some chronic illnesses may result in stigma-related stressors. Coping strategies used to cope with stigma-related stressors may be distinguished as voluntary coping or involuntary responses (Miller, 2001). Involuntary responses, whether conscious or unconscious, are not considered to be coping strategies. Coping strategies are conscious, voluntary efforts to control stressful situations or events. Coping efforts may be targeted at gaining primary or secondary control over the situation or event. Primary control is a sense of personal control over the environment and one's reactions. Coping efforts that result in primary control include problem solving and emotion regulation. Secondary control is aimed at adapting to the situation. Coping efforts resulting in secondary control include strategies to change the way one feels about the stressful situation such as positive thinking and cognitive restructuring (Compas et al, 2001).

Voluntary coping responses to stigma include disengagement tactics and engagement strategies (Miller, 2001). The coping strategies of normalization include some disengagement tactics such as minimization and selective association with chronically ill others. The coping strategies of normalization also include some engagement strategies such as problem solving and emotion regulation (primary control efforts), cognitive restructuring, distraction, and acceptance (secondary control efforts).

Adaptive vs. Maladaptive. Normalization is often viewed as positive and desirable (Dewis, 1989; Knafl, et al., in press; Wolfensberger, 1972). Some researchers conceptualize normalization as a coping strategy that should be supported and encouraged particularly when nurses identify that a family is experiencing difficulty coping with chronic illness (Knafl et al., in press). Evidence for this premise comes from Knafl, Breitmayer, Gallo, & Zoeller's (1995) work on the identification of family management styles used by parents with a chronically ill child. The thriving management style included normalization as a coping strategy and was found to be the most positive, beneficial style. However, while normalization is positive and desirable for many, there are conditions under which normalization ceases to be an effective and beneficial strategy for adapting to chronic illness. The following discussion addresses the foundation for the proposed framework (see Figure 1 on the next page for the proposed conceptual framework). First, the antecedents to normalization will be presented. Next, factors influencing normalization will be discussed. Subsequently, the adaptive and maladaptive outcomes of normalization will be identified. The proposed framework for normalization and its place within a chronic illness model will be described.

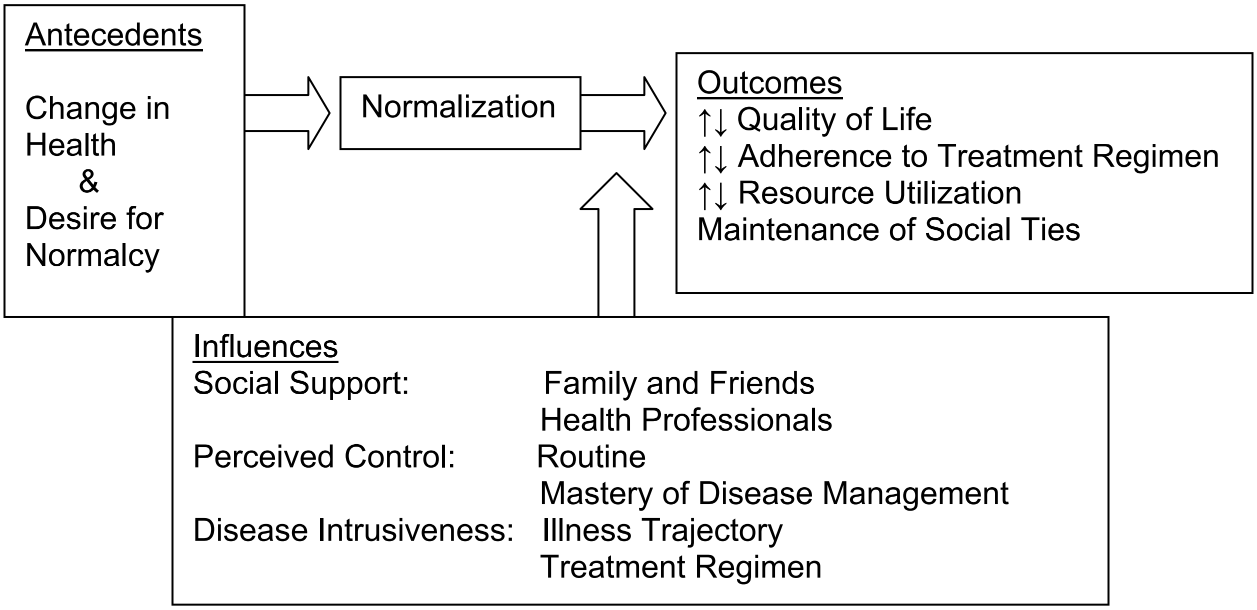

Figure 1: Proposed Conceptual Framework

Antecedents

The proposed conceptual framework was based upon the normalization research to date. Antecedents to normalization include a change in the individual's health status and a desire normalcy.

<u>Change in Health Status.</u> Normalization is an adaptive response to potential stigmatization. Chronic illness is a source of potential stigmatization. Thus, it is reasonable that an antecedent to normalization is the existence of deviance through change in health status (Deatrick et al, 1999; Hilton, 1996; Knafl & Deatrick, 1986; Miles, 1979; Rehm & Franck, 2000; Robinson, 1993; Royer, 1995; Wiener, 1975). The change in health status is the impetus for coping and adaptation. Often a change in health status requires the individual to

re-evaluate their abilities and perhaps lower their expectations based upon a new level of functioning (Wiener, 1975).

Desire for Normalcy. Another antecedent is the perception by the individual or family that normalcy is to be valued. For normalization, the individual or family must buy into the desire to be normal and to strive for normalcy versus acquiring a sick role or the role of an invalid. Normalization is often considered a Western, middle class Caucasian ideal, not necessarily embraced by all cultures or all social contexts (Anderson, 1986). For example, not all families view ill children from a normalcy framework (Anderson, 1986; Gravelle, 1997). The desire for normalcy is not a focus for all individuals and families experiencing chronic illness.

Influences

According to the proposed conceptual framework, the factors that influence normalization include social support from family, friends, and health professionals; perceived control personally, socially and environmentally; and the intrusiveness of the disease in terms of the illness trajectory and treatment regimen. The following is a discussion of these influences.

Social Support. The literature supports the idea that families who normalize with ease describe having social support. Social support affects health status and quality of life through its buffering effects on physical and emotional stress (Seeman, 1996; Stewart & Tilden, 1995). Normalization is influenced by the congruency of families' views (Miles, 1979; Hilton, 1996). Family members who share the same view, agree how to handle illness situations, and agree how to cope with the illness, normalize with less difficulty. Also, families that are well established in their neighborhoods have been found more likely to normalize than those families who have recently moved to a new neighborhood and/or live distant from relatives (Miles, 1979). Families who have social support and share similar views may find that relationships strengthen in working toward a common goal due to their shared views, shared goals, and the existence of previous bonds.

Obtaining social support is not always easy for individuals who normalize. Some health professionals do not share the philosophy that normalization is positive and desirable. Parents of hospitalized children have stated they felt criticized when they attempted to maintain the child's normal daily routine (such as bedtime) and set limits as they would at home (Robinson, 1993). Health professionals may impede normalization attempts in this way.

According to Robinson (1993), some health professionals equate normalization with denial, which many health professions believe to be maladaptive. It follows that some health professionals, in coming in contact with normalizing individuals who are not following recommended treatment regimens, would conclude that the individual was exhibiting denial. However, individuals and families who are normalizing generally acknowledge the illness's existence and seriousness (Hilton, 1996; Knafl & Deatrick, 1986). This disputes the existence of denial, per se, but underscores the importance of health care professionals being knowledgeable about normalization.

Chronically ill individuals and families require support and resources in order to cope successfully with chronic illness. An individual's ability to receive support from others may also be impeded by the normalization process. Some individuals may choose not to belong to organizations designed to support them in coping with their disease processes (Hilton, 1996). They disassociate from similar others in order to identify and interact with normal others. In doing this, these individuals may not receive information and support that would be valuable to coping with their condition.

Normalization may impede an individual from receiving support in another way. Individuals who are successfully normalizing may appear to health professionals as so normal that certain services and resources are not offered (Robinson, 1993). These individuals fail to emit cues that they need help from health professionals or others with whom they come in contact. In these ways, persons who normalize may find difficulty accessing social support resources. Health professionals need to be aware that while an individual or family appears successful in their efforts to normalize, there may be information or services that could meet less visible needs.

<u>Perceived Control.</u> Control is not identified as part of the definition of normalization but is a definite thread throughout the normalization literature. In the normalization literature, individuals and families identify the maintenance of a

routine as paramount in attempting to live as normally as possible. Families and individuals often view the maintenance of a "normal" family routine as pivotal to successful normalization (Cohen, 1995; Deatrick, 1988; Hilton, 1996; Hilton, Crawford & Tarko, 2000; Jerret & Costello, 1996; Robinson, 1993; Seppanen, Kyngas, & Nikkonen, 1999). This may fall under two of the elements identified by Knafl & Deatrick (1986): defining life as basically normal and engaging in behavior that demonstrates normalcy to others. Inherent in the ability to maintain a normal routine is the issue of controllability. In fact, in the extreme – e.g. those with obsessive-compulsive disorders – establishing a routine is done for the purpose of feeling in control and, thus, for reducing anxiety.

Jerret & Costello (1996) equated "being in control" to normalization for parents managing their child's asthma. Gerhardt & Brieskorn-Zinke (1986) emphasized mastery, which can be argued as the same as a sense of control (Wallston, 1991). Robinson (1993), Clarke-Steffen (1997) and Bossert, Holaday, Harkins, & Turner-Henson (1990) refer to individuals controlling the flow of information. Dewis (1989) also emphasized control in maintaining independence. Because control is a strong theme in this literature, perceived control is a probable influence of normalization.

Perceived control is "the belief that one can determine one's own internal states and behavior, influence one's environment and/or bring about desired outcomes" (Wallston, 1991, p. 5). This belief may or may not be rooted in reality. A person's sense of control over any one aspect of their life may change over time. In the health arena, positive and negative effects of control have been associated with health outcomes in chronically ill adults (Thompson & Collins, 1995). In general, those who maintain a sense of control will cope with situations better, experiencing less depression and anxiety than those individuals who do not feel a sense of control (Affleck, Tennen, & Gershman, 1985). However, some evidence suggests that individuals who initially believe they can exert control but are then unsuccessful may exhibit poorer health outcomes (Thompson & Collins, 1995). Reich & Zautra (1990) conducted an intervention study designed to increase older adults' perceptions of control. Those adults who scored high in internal locus of control demonstrated benefits from the intervention while those adults whose internal locus of control was low did not benefit from the intervention. Perceptions of perceived control may interact with the belief about the locus of influence thus affecting the outcomes of having a sense of control. In other words, if perceived control is attributed to external influences, the impact of having more control will be minimized.

Within normalization, control of social interactions involves manipulation of the individual's environment, behavior, and appearance, resulting in the maintenance of normalcy. Charmaz (1995) proposes that when control over the illness ceases there is surrender to the sick body and the individual relinquishes control over his or her own body. There is acceptance of the reality of the illness, not defeat. This relinquishing of control results in a view of the ill body as part of the self. Hence, such an individual would no longer be normalizing.

Disease Intrusiveness. Disease intrusiveness refers to the amount of lifestyle disruption experienced by individuals as a result of illness effects, treatment effects, and treatment requirements (Devins et al., 2001). Disease intrusiveness affects subjective well-being and health related quality of life. Physical aspects of the disease process and the treatment regimen may present barriers or threats to normalization. There is support in the literature that the trajectory of the illness may lead to a point where normalization ceases to be beneficial and results in a lowered quality of life. The length of time since diagnosis may impact normalization in terms of illness trajectory and because normalization sustained long-term can deplete energy. The more intrusive the illness, or the treatment, the more difficult normalization becomes (Deatrick, 1988; Gagliardi, 1991; Hilton, 1996). As an ill child grows, the ability to manage the child and the illness becomes more difficult due to the increased weight of the child and the development of further physical consequences related to the trajectory of the disease (Deatrick, 1988; Sawyer, 1992; Gravelle, 1997). The reverse is true as well. The intrusiveness of the treatment regimen upon normal life activities may be more pronounced during infancy or toddlerhood as supported by Hatton et al.'s (1995) research of parents caring for an infant or toddler with diabetes. From the adult perspective, an ill parent may find that having young children taxes the energy resources of the individual and their ability to normalize (Hilton, 1996). Normalizing in the face of such disease or regimen intrusiveness results in depleted energy that may be a precious commodity for someone who is chronically ill (Wiener, 1975; Royer, 1995). In these cases, normalization promotion may not lead to an optimum quality of life or be perceived as beneficial.

Outcomes

The adaptive outcomes of normalization are a positive quality of life, mastery of treatment regimens, increased resource utilization and maintenance of social ties. Maladaptive outcomes include a negative quality of life, noncompliance with treatment regimens, and lack of resource utilization.

Quality of Life*.* There is support from the literature that normalization can be positive and beneficial. Persons who normalize often reframe situations positively and are hopeful about their life (Robinson, 1993). Theoretically, this hope or sense of optimism results in a positive quality of life and allows them to cope with adversity and to focus on wellness and abilities, thus avoiding grief and depression. Robinson (1993) contended, after examining the benefits and costs of normalization in adults and children with chronic illness, that the benefits of hope outweighed the costs.

Quality of life is a subjective concept that is based on the value an individual attaches to life meaning. Essentially, quality of life is one's sense of well-being or satisfaction with life (Gulick, 1997). Well-being includes one's evaluation of life domains such as marriage and family, work, health, education, standard of living, and other domains. In other words, it addresses physical, psychological, and social components (Campbell, 1981). The quality of life goal for individuals with chronic illness often involves reaching an optimal level of functioning at the highest level of independence (Lubkin, 1986). Over time, individuals with chronic conditions continue to navigate the health care system with the goal of obtaining care essential for an adequate quality of life.

The costs of normalization may lead to a lowered quality of life for some individuals and families. To the extent that normalization can cause energy depletion, lack of support, and weakening of family bonds, individuals and families using normalization may experience a decreased quality of life (Deatrick, Knafl, & Walsh, 1988; Hilton, 1996; Robinson, 1993, Royer, 1995; Wiener, 1975).

Mastery. Normalization may also result in mastery of treatment regimens (Gerhardt & Brieskorn-Zinke, 1986; Jerret & Costello, 1996). This is the flip side of noncompliance. Normalization may result in increased compliance and confidence with treatment regimens and managing their illness (Gerhardt & Brieskorn-Zinke, 1986; Hilton, 1996; Jerret & Costello, 1996; Rehm & Franck, 2000). No conclusions can be drawn to predict for whom normalization results in compliance and for whom normalization results in noncompliance. There is a possible relationship between the concept of perceived control and compliance (Jerret & Costello, 1996). Compliance may be more likely and more easily attained in individuals who have a greater sense of control. Control has been discussed as an influence on normalization in a previous section.

Noncompliance. Some individuals and families that normalize present to health professionals as being noncompliant with treatment regimens (Anderson, 1986; Deatrick et al, 1999; Miles, 1979). This occurs because, when individuals and families normalize, they incorporate treatment regimens into their life by minimizing the disruption of normal life patterns (Deatrick et al., 1999). In order to merge the treatment regimens with normal life patterns, some individuals and families alter the regimen. It may be argued that health professionals who are knowledgeable about the promotion of normalization would be able to assist individuals and families to integrate a treatment regimen into normal life patterns. However, some treatment regimens are so intrusive that the gap between the individual's or families' acceptance of a "revised normal" and the requirements of the treatment regimen is too broad. The individual or family may choose simply to be noncompliant with the recommended treatment regimen or may reject the dream of normalcy and take on another role such as the sick role or the role of an invalid. In this case, normalization ceases to be an effective strategy, thus leading to a hastening of the illness trajectory as a result of non-compliance with the treatment regimen.

Resource Utilization. As discussed earlier, some chronically ill individuals seek out information from health professionals and support groups (Miles, 1979; Royer, 1995). This seeking of information results in increased resource utilization. Alternatively, some individuals engage in avoidance strategies where they limit contact with similar others (Royer, 1995). They do not attend support groups or seek information about their illness, resulting in decreased resource utilization.

Maintenance of Social Ties. Some families living with chronic illness experience a strengthening of family bonds (Dashiff, 1993; Haase & Rostad, 1994; Hilton, 1996). The experience of coping and managing chronic illness successfully as a family brought family members closer together. This may have been enhanced by the presence of working toward a common goal.

In addition to receiving social support, individuals and families that normalize are likely to maintain social ties, a positive outcome in and of itself. This maintenance of social ties is often a priority for individuals and families who normalize (Dewis, 1989; Rehm & Franck, 2000). This includes a child's participation in school, including academic and extracurricular activities (Rehm & Franck, 2000).

Explanation for the Outcomes of Normalization. Goffman (1963) emphasized the role of illness visibility in his work about stigma. He differentiated the responses of individuals who were discredited by visible stigma versus responses of individuals who were discreditable by a stigma that may be concealed and covered. The visibility of chronic illness may influence the choice to normalize or the ability to normalize successfully. Response to stigma-related stressors depends upon the individual's appraisal of the significance of the stressor and whether the individual has the resources to cope with the stressor

(Miller 2001). Thus, for some, the visibility of the illness may not impact normalization. In research conducted by Deatrick (1988) and Miles (1979), the illness visibility and duration did not impact normalization. In fact, Miles (1979) found that some of the most visibly disabled subjects used normalization as a coping strategy. The previous example of the woman who wanted a wheelchair so she could shop also disputes the influence of visibility on normalization. This illustrates the importance of the self-definition of normal. This example also demonstrates that individuals may normalize on different dimensions (physical, social, personal identity). The woman shopper was apparently more interested in normalizing her social activities than in normalizing her physical appearance to others.

Examination of the literature for trends related to illness visibility yielded no relationship between the choice to normalize and the success of normalization except in two instances. Among individuals with less visible illnesses, it was more difficult to determine how much information to disclose and to whom (Bossert et al., 1990). Rehm & Franck's (2000) research on children with HIV/AIDs supports the difficulty parents experienced in knowing what to disclose, when to disclose, and to whom. Consistent with Goffman's (1963) framework, these individuals are discreditable but can pass as normal, and thus avoid stigma, until they disclose. Alternatively, visibility of treatment effects impacted the normal husband-wife relationship in women diagnosed with breast cancer (Hilton, 1996). In this case, the visibility of the treatment effects discredits the individual thus creating stigma. A woman may be able to "pass" to outsiders, with the use of creative clothing or prostheses. However, she cannot “pass” with her husband due to the intimacy of the relationship. “Passing” is a way to deal with stigma by hiding the stigmatizing characteristic and presenting a normal appearance to others.

The analysis of the normalization literature based upon illness visibility was complicated by the lack of detail in certain research descriptions. For instance, a study examining coping in adults with multiple sclerosis did not describe the sample well enough to determine the degree of illness visibility. Individuals with multiple sclerosis may exhibit no outside signs of illness or the signs may be very subtle. On the other hand, these individuals may be very disabled. Thus, knowing the diagnosis is not enough information to determine the visibility of the illness. As one can see, bringing normalization into the quantitative arena may help answer some of these questions. The proposed conceptual framework identifies some of the factors that may moderate the outcomes of normalization and is described next.

Proposed Conceptual Framework

While the current literature base has developed the concept of normalization in terms of behavioral strategies used for normalization as well as the influences and benefits and costs that may accompany normalization, the interaction of normalization influences and their predictable relationship to one another and the outcomes has yet to be established. A proposed conceptual framework based on the current literature base follows. (See Figure 1 on page 21 for a diagram of the proposed conceptual framework.) Further research is needed to clarify these relationships.

Normalization is conceptualized as an adaptive, long-term process in which cognitive and behavioral responses change based on transitional situations that arise such as those associated with an alteration in condition or a change in social network. This conceptualization is consistent with Wiener's (1975) description of re-normalizing. Wiener asserts that, over time, individuals alter their view of what is normal based on the constraints imposed by the chronic condition. According to Wiener, this re-normalization may result in disruption of previously used strategies to maintain a specific level of "normal." Thus, normalization may be viewed as an overall adaptation mode comprised of several cognitive and behavioral coping strategies: acknowledgment of the seriousness of the disease condition; denial of disease impact; minimization of abnormal appearances, interactions, and routines; and incorporation of a treatment regimen into normal daily life. Normalization may occur at the individual, familial, or group level and may involve physical, social, or personal domains.

As supported by the literature, social support may affect the normalization process (Dashiff, 1993; Haase & Rostad, 1994; Hilton, 1996; Miles, 1979). This influence may result in positive or negative effects. It is theorized that social support, the quality of social interactions, the degree of perceived control over social interactions, and disease or treatment intrusiveness all affect the normalization process and the outcomes of that process. A possible outcome of normalization is altered quality of life. The degree of perceived control over social interactions, physical functioning and the environment may affect normalization and, subsequently, quality of life. Individuals with less perceived control in a general sense may have more difficulty maintaining social interactions, mastering treatment regimens and normalizing, resulting in poorer quality of life. Individuals with more perceived control in general might have more success normalizing, more success with integration of treatment regimens, and more success maintaining social ties, thus contributing to an increased quality of life. However, over time, these positive effects of normalization may diminish as the energy costs raise and affect individuals physically, psychologically, and socially.

A metastudy of the chronic illness literature has generated a model to explain the conflicting behaviors and outcomes observed in persons who are chronically ill. The concept of normalization fits within this model. The model is discussed next.

The Shifting Perspectives Model. The Shifting Perspectives Model, developed from a metasynthesis of 292 qualitative studies pertaining to chronic illness, is a model of chronic illness where the illness experience is described as a continually shifting process between two perspectives of the individual (Paterson, 2001). One perspective is ”illness in the foreground” and the other perspective is “wellness in the foreground”. These perspectives determine how individuals cope with chronic illness. The individual’s perception of reality and its context change, so too may the perspective of the individual, particularly if there is a threat to control. Disease progression, stigma-related stressors, and interactions with others focusing on dependence can threaten control (Paterson, 2001).

In the illness in the foreground perspective, the emphasis is on sickness, loss, suffering and the burden of the illness. Individuals using this perspective identify with the sick role. The positive aspect of this perspective is that individuals can conserve energy and resources. The individual can focus on learning about their illness and can obtain needed attention and care from others. On the negative side, individuals of this perspective can feel overwhelmed, can have difficulty fulfilling their pre-diagnosis roles and find it hard to attend to the needs of others (Paterson, 2001).

In the wellness in the foreground perspective, chronically ill individuals distance themselves from illness, describe their health as good despite decreased physical functioning, and attempt to find harmony between their self-identify and the identity as a result of the disease. The focus is on what is possible and normal. In this perspective, the individual accepts the illness while minimizing its significance and impact (Paterson, 2001). The identified cognitive and behavioral tactics in this perspective are consistent with normalization. Persons who normalize fit into this wellness in the foreground perspective. It can be proposed that adoption of the sick role is the polar opposite of normalization, similar to this model where illness in the foreground is the opposite of wellness in the foreground.

Sick Role Adoption. Normalizing is a process where individuals identify with normal others and seek to engage in typical activities. However, some individuals choose, instead, to identify with sick persons. This is referred to as adopting the sick role. In essence, adoption of the sick role is the polar opposite of normalization. In 1951, Talcott Parsons coined the term “sick role” and developed a model describing the phenomenon. In this model, individuals identify with being ill and take on that social role. Four main features comprise the sick role: (1) the sick person is exempted from the normal responsibilities consistent with their usual role; (2) the sick person is exempted from responsibility for the illness and has a right to be cared for – the responsibility is viewed as the physician’s responsibility; (3) the ill individuals is in need of the expertise of a physician and is helpless; and (4) the individual has an obligation to become well. Acknowledging this definition, Brown & Rawlinson (1975) developed a sick role measure based on the determination that acceptance of the sick role is consistent with how similar individuals perceive themselves to be with sick persons in the domains of worthiness, power, activity and independence.

Blackwell (1992) identified seven features of sick role behavior and management strategies for the behaviors. In addition to helplessness and the emphasis on physician responsibility, Blackwell notes that individuals may receive environmental rewards (care, attention) for the sick role and may exhibit interpersonal behaviors that sustain the sick role. Often the disability demonstrated by individuals is disproportionate to the disease process.

Interestingly, the management strategies that Blackwell identified for countering the sick role behaviors include: (1) redefining symptoms; (2) emphasis on self-management of symptoms; (3) enhancement of the healthy role; and (4) minimization of the sick role by the physician. These interventions sound very close to normalization that supports the idea that assuming the sick role is on the opposite end of the continuum from normalization.

Assumptions

This research study was guided by the following assumptions about normalization: normalization is viewed as predominantly a positive and desirable adaptation process; normalization is a process of interaction between cognitive and behavioral coping strategies to maintain the state of normalcy; normalization is a universal phenomenon in terms of chronic disease, not illness specific; and normalization can be measured cross-sectionally with a self report scale. These four assumptions formed the foundation for the conceptualization of normalization throughout the study.

Research Questions: Phase One

Although normalization is a universal phenomenon, not illness specific, the purpose of this study was to develop a measure of normalization utilizing participants diagnosed with a variety of rheumatological conditions. For phase one of this study, the research question was: (1) Can relevant items be constructed to constitute a summative measure of normalization?

Definition of Terms

Normalization. Normalization is an adaptation mode where individuals acknowledge the presence of illness, identify their life as normal based upon their view of what is typical for them, and engage in cognitive and behavioral strategies minimizing illness impact on prior patterns of social interaction and/or maintaining a usual appearance to others. It was operationalized by a self-report rating scale constructed during this phase of the study and, later, utilized in phase two of the study.

Research Questions: Phase Two

For phase two of this study, the research questions were the following: (1) Is the developed normalization measure better described as a unidimensional measure or a multidimensional measure? (2) What are the psychometric properties of the developed normalization measure? (3) What is the relationship between scores on the normalization measure and measures of the following constructs: perceived control, disease intrusiveness, quality of life, and social ties? (4) Are these relationships consistent with the proposed conceptual framework? (5) Are there differences in normalization due to type of rheumatological condition? and (6) What is the relationship between normalization and the length of time since diagnosis?

Specifically, the following hypotheses were tested:

1) There is positive relationship between normalization and problem focused coping.
2) There is a negative relationship between normalization and emotion focused coping.
3) There is a positive relationship between normalization and sick role *non*acceptance.
4) There is no correlation between normalization and social desirability.
5) People with fibromyalgia score lower on normalization than people without fibromyalgia.
6) There is a negative relationship between length of time since diagnosis and normalization.
7) There is a positive relationship between perceived control and normalization.
8) There is a negative relationship between normalization and illness intrusiveness..
9) There is a positive relationship between normalization and quality of life.
    a. The variance in quality of life is explained by the linear combination of perceived control, illness intrusiveness, and normalization.
    b. When controlling for illness intrusiveness and perceived control, normalization uniquely explains the variance in quality of life.
10) There is a positive relationship between normalization and social ties.

   a. The variance in social ties is explained by the linear combination of perceived control, illness intrusiveness, and normalization.
   b. When controlling for illness intrusiveness and perceived control, normalization uniquely explains the variance in social ties.

11) Illness intrusiveness moderates the relationship between normalization and quality of life.
   a. Among people with *high* illness intrusiveness, the relationship between normalization and quality of life is negative.
   b. Among people with *low* illness intrusiveness, the relationship between normalization and quality of life is positive.

12) Perceived control moderates the relationship between normalization and quality of life.
   a. Among people with *high* perceived control, the relationship between normalization and quality of life is positive.
   b. Among people with *low* perceived control, the relationship between normalization and quality of life is negative.

CHAPTER III

METHODOLOGY: PHASE ONE

Research Design

The study consisted of two phases. Phase one focused on developing and refining a normalization assessment measure. The initial measure was administered to 15 individuals in focus groups of 3-4 as a pilot study. Refinements were made based upon revelations from the pilot study.

Research Setting

The research setting was a rheumatology practice in the south plains region of Texas. A local rheumatologist office allowed access to clients. The practice is located in a city with an approximate population of 200,000. Based upon census statistics from 2000, the population of the city is 49% male and 51% female. Adults 21 years and over comprise 67% of the population. Sixty-one percent of the city's population is white. Persons of Hispanic or Latino descent comprise 27% of the city's population. The remaining population is African American, American Indian, or Asian (Areaconnect, 2002).

Sample

Criteria for Sample Selection. The sample selected for both phases consisted of adult individuals diagnosed with rheumatoid arthritis, lupus, osteoarthritis, or fibromyalgia. These conditions were selected because: (1) individuals experiencing arthritis have been studied previously in the normalization literature; (2) these particular chronic illnesses have variability in the range of symptoms; and (3) individuals with these conditions were readily accessible. While there are many chronic illnesses meeting the above criteria, these rheumatology conditions offered variability of disability, yet all of the identified conditions exhibit musculoskeletal involvement and pain.

Fibromyalgia is a rheumatological condition of unknown etiology where the individual experiences chronic widespread pain. In particular, the individual complains of musculoskeletal aching and stiffness in multiple tender points. Approximately 2% of the U.S. population is diagnosed with fibromyalgia, with diagnosis occurring seven times more frequently in women than men (American College of Rheumatology, 2002). No current cure exists. Among individuals with fibromyalgia, the disability rate may be as high as 44% (Arthritis Foundation, 2002).

Rheumatoid arthritis (RA) is an inflammatory condition also of unknown etiology that results in chronic pain, stiffness, swelling and loss of function in the joints. More than 2 million Americans have rheumatoid arthritis, with 75% being women. Treatment is aimed at preservation of function and prevention of joint deformity through the use of pharmacologic intervention (American College of Rheumatology, 2002).

Osteoarthritis (OA) is a degenerative joint disease that has symptoms similar to rheumatoid arthritis. Osteoarthritis affects 21 million Americans and is the most common type of arthritis. Pharmacologic intervention can help relieve pain and improve joint function (American College of Rheumatology, 2002).

Systemic Lupus Erythematosus (SLE) is a chronic inflammatory condition that results from an abnormality of the immune system. While lupus affects many bodily systems, arthritis in one or more joints is commonly observed. Anti-inflammatory and immunosuppressive medications may be helpful during the course of this condition (American College of Rheumatology, 2002).

Criteria for Inclusion. The criteria for inclusion in the study were: English speaking adult 18 years or older, and diagnosed with one of the four rheumatological illnesses greater than three months. This 3-month window allowed time for pharmacologic intervention. Criteria for exclusion included individuals with dementia and individuals with terminal illnesses.

Due to the variability of incidence rates for the four identified conditions, it was not expected that the sample distribution among the diagnoses would be equal or even approximately equal. The sample was expected to have more women than men given that several of the conditions are more common in women than men.

Nature and Size of the Sample. Adult English speaking men and women were recruited for participation in this study. Because the emphasis of this study was to develop and validate a measure, conversion of the instrument into other languages was not prudent at this time. Furthermore, there may be cultural differences in the conceptualization of “normal” (Anderson, 1986). Once a valid and reliable instrument has been developed in English, future research may address the development of a normalization measure in other languages, if appropriate. Thus, non-English speaking individuals were excluded from the study. Fifteen individuals participated in five focus groups for phase one aimed at obtaining feedback about the clarity of the initial version of the normalization measure.

Participants met in groups of 3-4 people and gave feedback about the initial set of items developed for the normalization instrument. The individuals ranged in age from 33 years to 65 years. All participants were Caucasian females except for one participant who was a Caucasian male. Three participants identified fibromyaligia has their primary rheumatological condition, one indicated a diagnosis of lupus while the remaining participants were diagnosed with rheumatoid arthritis.

Human Subjects’ Rights. Human subjects’ rights were assured through informed consent procedures. These procedures were in compliance with Federal government regulations established in the Health Insurance Portability and Accountability Act (HIPAA). Additionally, the Institutional Review Board

(IRB) policies and procedures of both Vanderbilt University and Texas Tech Health Science Center were followed.

The HIPAA Act of 1996 was enacted to provide two types of protection to individuals. Title 1 of the HIPAA Act provides for health insurance reform particularly for individuals who change or lose their jobs. Title II includes Administrative Simplification provisions for the Department of Health and Human Services. These provisions address the establishment of national standards for electronic health information systems. In addition to standards for electronic health transactions (including claims, enrollment, eligibility, payment and coordination of benefits), the national standards are required to address privacy and security issues (Centers for Medicare & Medicaid Services; U.S. Department of Health and Human Services Office for Civil Rights).

For investigators conducting research, HIPAA regulations relate to the confidentiality of medical records and information about clients. IRB policies for both Vanderbilt University and Texas Tech Health Science Center also provide protections for subject confidentiality, informed consent, and minimizing the potential risks for subjects participating in the study. An IRB application was submitted first to Vanderbilt University and then Texas Tech University for approval of the dissertation research. This researcher was accountable to both IRBs. This researcher completed the required human subject rights online courses, tutorials and tests mandated by Vanderbilt University and Texas Tech Health Science Center for researcher compliance. Additionally, the Texas Tech Health Science Center required a HIPAA training workshop for researchers which was completed. The specific strategies employed in this study to meet the HIPAA regulations and IRB policies are described under the headings “Methods for Subject Recruitment” and “Data Collection Methods”.

Methods for Sample Recruitment. For this study, the recruitment of subjects complied with HIPAA protections. After a waiver was obtained (Principal Investigator’s Request to Use and Disclose Protected Health Information) from the IRB, the cooperating rheumatologist compiled a list of clients from his practice who had been diagnosed with one of the following conditions (RA, SLE, fibromyalgia, and OA). With funds provided from the researcher, the physician sent a letter to 470 clients on the list who met the inclusion criteria. The letter explained the opportunity to participate in research being conducted by this investigator. A preaddressed and stamped postcard accompanied the letter. Individuals indicated whether they consented to having this researcher contact them about participating in the study by returning the preaddressed postcard to the researcher. They also were asked to give their name, address and phone number if they indicated assent. Individuals who did not wish to assent did not return the postcard. This was consistent with HIPAA and IRB guidelines. One hundred thirteen individuals returned postcards.

The researcher then contacted individuals by phone. The study was described to the potential participants. Interested individuals were given the option of participating in phase one or phase two. For phase one, 15 individuals from those returning postcards were recruited to participate in a focus group session. Because of scheduling difficulties, more than one focus group session was scheduled with smaller numbers (3-4 participants) in each group than is typical for focus groups. This kept the group size manageable and allowed for changes to be made in the instrument before administration to the next group.

It was conceivable that persons in the sample would know other persons who may meet inclusion criteria. Thus, individuals identified through this “snowball” procedure also were asked to participate in the study. In cases where individuals advised the researcher of other individuals who may be interested in participating, the researcher provided the informant with a letter from the researcher and a postcard. The informant delivered the letter and postcard to the identified possible participant, thus maintaining confidentiality. As above, the postcard provided a venue whereby the individual could indicate assent for the researcher to contact them about participation in the study. An additional 14 participants were identified in this manner.

Data Collection Methods

Procedures. Phase one of this study involved the initial development of the normalization measure. The previous 51 studies that focused on normalization contributed to my understanding of normalization and provided the basis for the initial set of proposed items of the normalization scale.

Experts familiar with the normalization literature and scale development reviewed the items I developed for clarity, conciseness, and relevancy. The experts included the members of my dissertation committee at the time and Kathy Knafl, Ph.D., a professor of nursing at Yale University. Dr. Knafl, a medical sociologist, has published extensively on normalization and had agreed to be a co-sponsor of my NRSA application back in 1998.

The dissertation committee provided expertise in scale development and the proposed correlates. Dr. Ken Wallston has extensive expertise in scale development and perceived control. Dr. Nancy Wells has expertise in quantitative research and quality of life. Dr. Carole Ann Bach also has expertise with the concepts quality of life and perceived control. Her clinical area of expertise is rehabilitation nursing where normalization is an important concept. Dr. Peggy Thoits has expertise in deviance, stigma, social support and had a sociology background (the disciplinary origin of normalization). Dr. Joe Hepworth is expert in quantitative research and on stress and coping. After review by my expert panel, the preliminary version of the normalization assessment measure consisted of 67 items. It was this version of the measure that was administered to participants during focus group sessions.

Each focus group session was audiotaped and later transcribed to ensure that all comments were accurately captured. At the beginning of the group, consent letters were handed out and read, giving ample time to answer participants' questions. Once the consent forms had been signed and turned in, the individuals were given a packet including the initial version of the normalization measure, a feedback form, and a demographic form. The feedback form allowed participants to respond to the clarity of the instrument and wording of the items and anything else that came to mind about the experience of filling out the normalization measure. Individuals completed the packets identified by a unique code number for each participant, thus maintaining confidentiality. After all individuals had completed the packet, the researcher asked for verbal responses to the developed measure. While the written feedback provided important information about the tool, some individuals preferred verbal outlets. It was also the case that something verbalized by one individual triggered additional thoughts and comments in another individual, thus yielding more feedback. The same version of the normalization measure was used with all participants; however, it was evident after the first focus group that instructions were required on the form. Instructions were added for the later focus groups.

RESULTS: PHASE ONE

As a result of the feedback from the focus group participants, the initial 67 item measure was trimmed down to 36 items (see Appendix B). Some initial items were worded negatively—e.g., “Even when I have pain, I don’t behave as if I’m in pain”--which caused participants to have difficulty responding. The awkwardly worded items were reworded or deleted. Some items were identified by the focus group participants as vague while other items were worded without extremes thus encouraging participants to answer “some of the time.” Those items were either re-worded or deleted from the instrument. Additionally, the responses initially were on a 1-4 scale ranging from “Most like me/All of the time” to “Most unlike me/Never.” After consultation with my advisor, an expert on instrument development, it was decided to change the response scale to seven options ranging from “Not at all true for me” to “Very true for me.”

METHODOLOGY: PHASE TWO

Sample and Recruitment Procedures

Methods for Sample Recruitment. The researcher phoned or emailed all potential participants who had not attended a focus group in phase one. The study was described and individuals were asked if they wished to participate in phase two of the study by completing a set of mailed questionnaires. Ninety-eight individuals from those initially recruited for this study agreed over the telephone to complete mailed questionnaires.

Because the desired sample size was 150, a second round of recruitment letters were sent to 259 of Dr. Ratnoff’s patients. The patients include in this mailing were new patients who had not received a letter in the earlier mailing. Additionally, a second rheumatologogy practice was utilized to augment the sample recruitment for phase two. A large rheumatology office in the same town allowed the researcher to display a sign advertising the study in each of six examination rooms. Stamped postcards were placed below each sign. Interested persons completed the postcard and placed the postcard in the mail, or if they gave the postcard to the nurse, the nurse put it in the outgoing mail box at the front desk.

In order to maximize recruitment efforts, a table was also procured at a local arthritis walk advertising the study. The researcher passed out postcards to individuals who were acquainted with someone diagnosed with one of the identified rheumatoid conditions. Some of the individuals with one of the targeted diagnoses, who were at the walk, opted to take packet rather than have it mailed to their home. Fifty packets were distributed at the arthritis walk.

Of the 318 individuals contacted by these various methods, 300 agreed to participate. The remaining 18 individuals either declined or the phone number on the postcard was no longer valid.

<u>Nature and Size of the Sample.</u> A sample size of at least 150 respondents was deemed by my committee as minimally appropriate for determining the psychometric properties of the normalization instrument. With this sample size, an effect size (i.e., correlation) of 0.20 could be detected with a .70 power and an effect size of 0.30 could be detected with a power of .95 (Polit, 1999, p. 495). Desired power was set at .80 with alpha set at .05.

One hundred fifty two participants returned the questionnaires to the researcher, a 50% response rate. The phase two sample included predominantly female participants (n=116; 76.3%) while males (n=35) made up 23% of the sample. One participant did not indicate gender. Eight percent identified themselves as single, while 35.3% reported being married or partnered.

Divorced and widowed participants comprised 55.3% of the sample. The majority of participants had only completed high school (47.7 %), while 4% of participants failed to graduate from high school. A college degree had been obtained by 17.9% of the sample and 24.5% of subjects had attended college without obtaining a degree. The ethnicity of participants included 89.3% Caucasian individuals with 12.6% of those individuals reporting a Hispanic origin; 9.3% of the sample identified themselves as African American, and 1.4% indicated an American Indian or other ethnic background.

Of the 152 participants, 79 individuals indicated they had been diagnosed with rheumatoid arthritis (43% diagnosed for 15 years or less; range = 1 to 44 years) while 37 individuals reported a diagnosis of osteoarthritis (50% diagnosed for 10 years or less; range = 1 to 37 years). There were fourteen persons who did not specify the type of arthritis (40% diagnosed for 10 years or less; range = 0 to 46 years). Eighteen participants were diagnosed with lupus and 21 respondents indicated fibromylagia (67% diagnosed for 10 years or less; range = 1 to 15 years) as a diagnosis (81% diagnosed for 10 years or less; range = 1 to 29 years). Some individuals reported more than one diagnosis, thus the sum of diagnosed individuals by condition is greater than the number of participants.

Data Collection Methods

Procedures. The second phase of this study used the 36-item normalization measure developed in phase one. This measure, along with several other measures described subsequently, were used to examine the psychometric properties of the normalization instrument and to explore the relationship of normalization to its influences and the outcomes based upon the conceptual framework.

After contact by phone as described above, participants who indicated assent were mailed a packet. The packet included a letter from the researcher, the questionnaires, a demographic form, two informed consent letters and a stamped, addressed return envelope (see Appendix B for the questionnaire). The questionnaires and demographic forms were numbered with a unique code in order to maintain confidentiality. For individuals who may have limited ability to write, the researcher's letter offered the alternative of completing the questionnaires with the researcher by telephone. One participant contacted the researcher about completing the questionnaires over the telephone. Upon further discussion, the participant revealed that she had a granddaughter who she preferred to read her the questions but she wasn't sure this was allowed. The researcher assured the participant that this would be all right. After completion of the questionnaires, participants mailed back the packet in the addressed, stamped envelope provided. Participants kept one copy of the consent form for their records. Four weeks after the initial mailing to those who assented to receiving packets, a reminder postcard was mailed (following the recommendation of Bourque & Fielder, 1995).

Demographic Questionnaire. A questionnaire was developed to determine demographic and background information concerning the participants. The following variables were assessed: sex; age; racial and ethnic background; type of rheumatic condition; years since diagnosis; other diagnoses; education level; marital status; work status; family members living in the home; and age of family members.

Normalization Measure. Normalization was measured using the instrument constructed in phase one of this study. See Appendix B for the items of developed normalization measure.

Perceived Control Measures. Perceived control was measured using two instruments, one of which was a portion of the Rheumatoid Attitudes Index (RAI; DeVellis & Callahan (1993) and the other was an adaptation of the Perceived Health Competence Scale (Smith, Wallston, & Smith, 1995),

Helplessness is a lack of perceived control (Wallston, 1991). In helplessness, individuals anticipate that their efforts will be unsuccessful. This expectation is thought to be based upon previous life experience where the individual's efforts resulted in undesirable consequences that were uncontrollable and unpredictable (DeVellis & Callahan, 1993). Thus, there is a significant negative relationship between control and helplessness.

DeVellis & Callahan (1993) developed a 5-item measure of helplessness from the Rheumatology Attitudes Index (RAI) that can be used to assess perceived control in persons with a variety of rheumatological conditions. The full RAI contains a 5-item subscale that measures helplessness in the face of a rheumatological condition. The original 15-item RAI and the RAI helplessness subscale are correlated at .79 (DeVellis & Callahan, 1993). The RAI is a modification of the Arthritis Helplessness Index both of which have demonstrated good predictive validity in relationship to a range of arthritis activity indicators that do not rely on self report. The authors do acknowledge, however, that concurrent validity of the RAI is difficult to demonstrate due to the nonexistence of a broader general measure of helplessness. For this study, Cronbach’s alpha for the helplessness subscale was .78.

A positive indicator of perceived control was also assessed using the Perceived Medical Condition Self-Management Scale (PMCSMS) developed by my advisor, Ken Wallston. This 8-item measure is based upon the Perceived Health Competence Scale (Smith, Wallston, & Smith, 1995) and is as yet unpublished. However, Ken Wallston (personal communication, January, 2003) assured me that this new condition-specific version of the PHCS should be at least as reliable and valid as the more general health-related measure upon which it is based. The PMCSMS was chosen for its specificity to management of medical conditions. The PMCSMS is addresses perceived competence for management of the condition while the Perceived Health Competence Scale is an intermediate level of specificity for beliefs related to one's health. For this study, Cronbach’s alpha for the PMCSMS was .84, and the PMCSMS correlated -.63 ($p < .001$) with the helplessness subscale of the RAI.

The RAI and the PMCSMS were combined into an index of perceived control by first converting the RAI and PMCSMS scores into z-scores; then the standard score for helplessness was multiplied by -1 and the two standard scores were summed. This perceived control index was used for all of the statistical analyses related to perceived control.

Illness Intrusiveness Measure. Devins et al. (2001) developed a 13-item disease intrusiveness measure that indicates the extent of illness and treatment interference with life domains. Disease intrusiveness was assessed using the Illness Intrusiveness Rating Scale (IIRS) developed by Devins et al. (2001). The IIRS consists of three subscales: relationships and personal development; intimacy; and instrumental. Despite the subscale structure, the IIRS is often computed as a total score. In a study using eight different illness conditions (including RA, OA and SLE), reliability (alpha) coefficients ranged from .82 - .94 for total scale scores. Test-retest reliabilities of the total IIRS scores ranged from .79 - .85. The instrument is stable across disease groups (Devins et al., 2001). For this study, Cronbach's alpha for the total IIRS was .96. Validity of the measure has been demonstrated across patient populations with a wide variety of disease characteristics, treatment factors and diagnoses. The measure has performed as expected when examining the association of illness intrusiveness with disease characteristics and treatment variables as well as its relationship with subjective well-being and emotional distress, thus contributing to the construct validity of the measure. Additionally, discriminant validity has been shown by the finding that illness intrusiveness is not correlated with defensive response styles (Devins et al., 2001).

Quality of Life Measures. Quality of life may be determined by assessing health related quality of life and subjective well-being. Health related quality of life encompasses, among other things, the daily limitations experienced by an individual due to physical symptoms of disease. Quality of life was assessed using several instruments. Health-related quality of life was measured a section of the Multidimensional Health Assessment Questionnaire (MDHAQ) developed by Pincus, Swearingen & Wolfe (1999). The MDHAQ includes the Modified Health Assessment Questionnaire, advanced activities of daily living, and psychological items in the format of the Health Assessment Questionnaire (Fries, Spitz, Kraines & Holman, 1980), visual analog scales for pain and fatigue, and the Rheumatology Attitudes Index (DeVellis & Callahan, 1993). Although the HAQ is considered a standard for health status assessment of individuals with rheumatoid illness, the MDHAQ limits the floor effects observed with the HAQ and the modified HAQ. Test-retest reliability using kappa scores have ranged from 0.65 to 0.81 ($p<0.001$). Convergent validity is significant at $p < 0.001$ using several other instruments (Spearman's rho coefficients have ranged from .32 - .75). Although the RAI is embedded within the MDHAQ, it was used as a measure of helplessness, as discussed previously, and was not scored for use as part of the quality of life index. Eighteen items directed toward assessing difficulty in carrying out activities of daily living were scored for use in the quality of life index. Cronbach’s alpha of these 18 items for this study was .92.

Subjective well-being was measured using the 5-item Satisfaction With Life Scale (SWLS) developed by Diener et al. (1985). Researchers using the SWLS have reported coefficient alphas ranging from .79 - .89. Test-retest reliability appears more stable when the time interval is less than 10 weeks (.64 - .82) (Pavot & Diener, 1993). Correlations between the SWLS and other measures of subjective well-being ranged between -.32 and .62 in a sample of college students (Diener et al., 1985). When compared with emotional well-being measures, the scale demonstrates discriminant validity. Construct validity has been shown with other self-report and external criteria measures (such as interviewer ratings and reports of informants) for subjective well-being and life satisfaction. In this study, Cronbach’s alpha for the SWLS was .89.

Positive and negative affect were measured using the 20-item Positive and Negative Affect Schedule (PANAS) developed by Watson, Telegen, & Clark. (1988). Ten items on the PANAS assess positive affect, while the other 10 items assess negative affect. The PANAS demonstrates test-retest stability across various time periods ranging from .39 -.71. Cronbach’s coefficient alpha reliabilities range from .86 - .90 for the positive affect subscale and .84 - .87 for the negative affect subscale (Watson et al., 1988). Various time frames can be used with this instrument: e.g., at this moment; today; the past few days or week; the past few weeks, month or year; or in general. For this study, participants were asked to respond to the items with how they felt in *the past few weeks*.

Construct validity has been examined and demonstrated with other mood scales such as the State Trait Anxiety Scale and the Beck Depression inventory. For this study, Cronbach's alpha was .90 for the positive affect subscale and .93 for the negative affect subscale.

A quality of life index was created using the functional items of the MDHAQ, the Satisfaction with Life Scale, and the PANAS. First, the four separate scores were standardized into z-scores. Because life satisfaction was viewed by this investigator as the primary determinant of quality of life, the SWLS z-score was weighted three times the z-scores for the MDHAQ and the two PANAS subscales. The formula used to calculate the quality of life index was: QOL=3*z(SWLS) + z(PANAS positive affect) – z(PANAS negative affect) – z (MDHAQ).

Social Ties Measure. Social ties are the people with which an individual has a personal relationship. Often used synonymously with social network, social ties allow in individual to give and receive support. Social ties were determined using a 3-item measure taken from the Social Health Scale developed by Donald et al. (1978). In research by Smith & Wallston (1992), alpha reliability of this brief scale was .69 and test-retest reliability averaged .76 at one year. In unpublished data, this measure of social ties correlated positively with measures of psychological adjustment, quality of emotional social support, and availability of instrumental social support in Wallston's longitudinal panel studies of persons with rheumatoid arthritis (Ken Wallston, personal communication, 2003). Cronbach’s alpha for the social ties measure in this study was .80.

Coping Measures. Convergent validity of the new normalization measure was examined using selected subscales of the Coping Orientations to Problems Experienced (COPE) Questionnaire. This instrument, developed by Carver, Scheier, & Weintraub (1989), is a self-report measure of coping responses that people use when they confront difficult or stressful events in their lives (Carver et al., 1989). Both adaptive and maladaptive coping styles are included in the instrument. Respondents indicate the frequency with which they use each coping strategy to deal with stress. Responses range from 1 indicating, “I usually don’t do this at all” to 4 “I usually do this a lot”.

The full COPE consists of fifteen subscales with four items each. Eight of the 15 subscales were chosen for this study: Active Coping, Planning, Suppression of Competing Activities, Positive Reinterpretation, Acceptance, Denial, Behavioral Disengagement and Mental Disengagement. In the study by Carver, Scheier, & Weintraub (1989), the selected subscales demonstrated the following reliabilities: Active Coping (alpha = .62), Planning (alpha = .80), Suppression of Competing Activities (alpha = .68), Positive Reinterpretation (alpha = .68), Acceptance (alpha = .65), Denial (alpha = .71), Behavioral Disengagement (alpha = .63), and Mental Disengagement (alpha = .45). Convergent and discriminant validity have been demonstrated (Carver, Scheier & Weintraub, 1989).

The selected subscales of the COPE were grouped into two summary indices: a problem focused coping index (Cronbach's alpha = .88) and an emotion focused coping index (Cronbach's alpha = .81). The problem focused coping measure contained the following subscales: Positive Reinterpretation, Acceptance, Suppression of Competing Activities, Active Coping, and Planning. Behavioral Disengagement, Denial, and Mental disengagement comprised the emotion focused coping measure.

Sick Role *Non*Acceptance Measure. Additionally, convergent validity was established by using an adaptation of the Sick Role Acceptance Scale that was originally developed by Brown & Rawlison (1975). Adopting the sick role is considered the polar opposite of normalization so, for the purpose of this study, the Sick Role Acceptance Rating Scale item values were scored in such as manner as to reflect sick role *non*acceptance. The Sick Role Acceptance Rating Scale consists of a number of bi-polar sets of adjectives (e.g., good-bad; clean-dirty) which the respondent completes twice: once as "myself," and a second time for "most persons who are sick." For each bi-polar rating scale, a difference score was calculated by subtracting the "most persons who are sick" rating from the "myself" rating. The difference scores were squared and then averaged to produce a sick role *non*acceptance score total. The higher the resultant score, the more the participant saw themselves as distant from most other sick persons; thus, high scores signify the nonacceptance of the sick role. For the squared difference items on this measure, the Cronbach's alpha was .69.

Social Desirability Measure. Discriminant validity was established using a measure of social desirability bias. Normalization and social desirability are considered distinctly different concepts and, therefore, there should not be any correlation between normalization and social desirability bias. The measure of social desirability bias used in this study was the Strahan and Gerbasi (1972) 10-item shortened version of the Marlowe-Crowne Social Desirability Scale. Kuder-Richardson reliabilities of this shortened scale ranged from .62 - .75 among samples of university students (Strahan & Gerbasi, 1972). For this study, however, Cronbach's alpha for the shortened measure was only .45.

DATA ANALYSIS

Data were entered into an SPSS-PC computer file by the investigator. Reliability of data entry was verified by a second coder who randomly re-entered 15 (10%) of the returned questionnaires. Out of 3405 fields, only 6 errors were discovered yielding an error rate of .0018. Thus, it was decided that the initial data entry was accurate and the data were ready for analysis. The mean of other subjects on a given item was used for missing or incomplete data.

Analyses were conducted using the SPSS-PC statistical program package, Version 13. Descriptive analysis of the normalization scale was conducted. Measures of central tendency and dispersion were evaluated for each item and the total scale score. Also, a histogram and boxplot of the total score was examined to assess the shape of the distribution. An exploratory principal components factor analysis was conducted to determine how many factors underlie the item set and to confirm the grouping of items created during scale development. Item (scale) analyses were conducted to compute the alpha reliabilities of all of the summated scales.

Correlational analyses between two variables were conducted using both Pearson product-moment correlations and, in case some of the variables were not normally distributed, Spearman's rank-order correlation. Additionally, a simple correlation was computed within each diagnostic category to examine the relationship between normalization and length of time since diagnosis. Because of the number of correlations computed, inflation of type 1 error was a concern. For this reason, the significance level for the correlational statistics in this study was set at $p < .01$.

Multiple hierarchical regressions were conducted to determine the contribution of normalization, illness intrusiveness, and perceived control in explaining the variance in quality of life and maintenance of social ties. Hierarchical regression analyses were also used to test the moderational hypotheses. In those analyses, interaction terms were constructed by multiplying the mean centered normalization score by the mean centered illness intrusiveness score or the mean centered perceived control score.

CHAPTER IV

PHASE TWO STUDY RESULTS

Unidimensional versus Multidimensional. The first research question for Phase Two asked whether the developed normalization measure is better described as a unidimensional measure or a multidimensional measure. An exploratory factor analysis was conducted to determine whether the 36 item scale administered to the Phase Two sample was unidimensional or multidimensional. Utilizing SPSS-PC version 13, a principal components analysis with an orthogonal (Varimax) rotation for components with eigenvalues greater than 1.00 revealed the potential for 10 underlying factors explaining 71% of the variance. The Scree plot (see Figure 2 on the next page) was examined to help determine exactly how many factors were present.

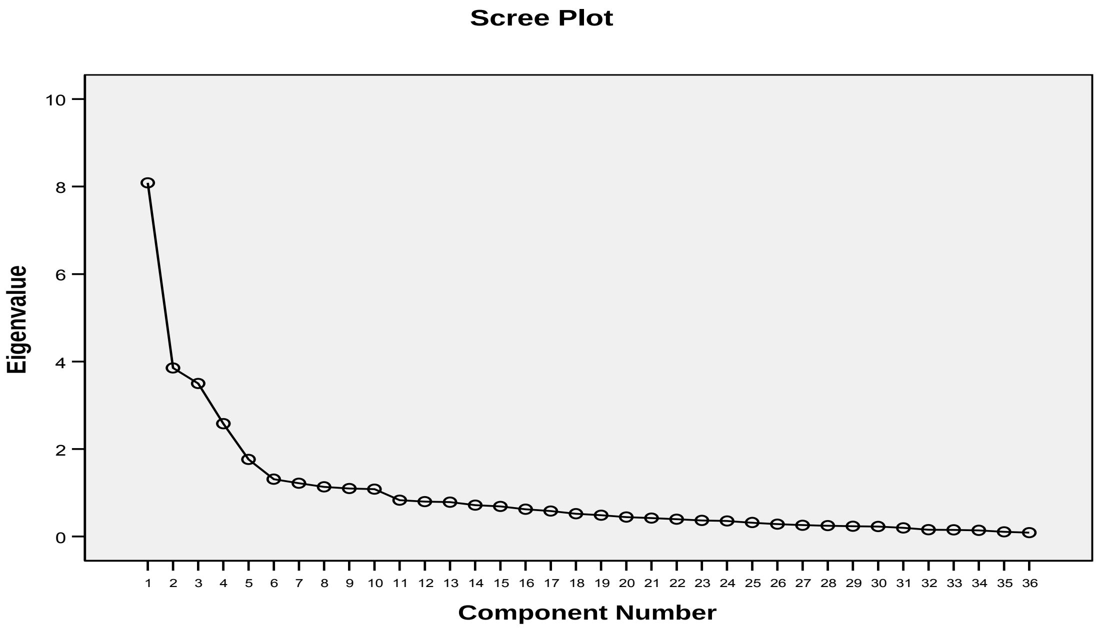

Figure 2: Scree plot

Conceptually, the organization of the 10 potential factors did not seem to be reasonable in the development of this instrument. Furthermore, 10 factors were many more than I had envisioned when I constructed the instrument, and observation of the Scree plot was not all that helpful in deciding how many factors were present in the data. Additional principal components analysis forcing four, and then five, factors and using both a Varimax (orthogonal) and an Oblimin (oblique) rotation did not yield any further clarity with respect to the possible multidimensionality of the instrument. Due to lack of clear delineation of the underlying factors and the fact that the first principal component explained twice the variance as the second and subsequent components, it was decided to treat the instrument as a unidimensional measure for the rest of the analyses.

Using SPSS's scale analysis procedure, it was determined that the original 36 item normalization scale had a Cronbach's alpha of .82. Although this demonstrated adequate internal consistency, because the measure was to be treated as a unidimensional instrument it was thought that a 36 item tool was too long to be useful to other researchers. Thus, the measure was further trimmed to the current 20 items by examining corrected item-total correlations to determine which items were most reflective of the main construct being measured. Twelve items that correlated poorly with the other items or failed to add to the overall internal consistency of the scale were eliminated. Additionally, the four reverse-worded items were eliminated from the measure due to questionable performance and the desire to produce a user-friendly instrument. Two items on the scale unexpectedly correlated slightly negatively with some of the other scale items. One of those items referred to hiding the fact that the individual has the condition, while the other item stated that excuses were given for accidents. Conceptually these two items were deemed integral to the construct of normalization so, notwithstanding their poor correlation with the other 18 items, those two items were left in the instrument to boost its content validity. Despite the inclusion of those two items, the Cronbach's alpha of the 20-item normalization measure utilized in the remainder of this dissertation is a respectable .86. (See Appendix B for the original 36 item measure, and see Table 3 on page 70 for the final version of the normalization scale.)

The second research question asked: What are the psychometric properties of the final normalization measure? Before addressing this question, descriptive statistics regarding the final normalization measure are presented.

Descriptive Statistics. The mean normalization scale score for the full 20 items is 109.29 with a standard deviation of 17.78. The mean item score is 5.46 with a standard deviation of .89. (See the mean item statistics in Table 4 on page 71 and Figure 3 on the next page for the histogram of the normalization mean item scores). The distribution of the normalization measure is negatively skewed (with most scores at the higher end) and positively kurtotic (i.e., peaked). Because of the skewed distribution, both parametric and nonparametric correlational statistics are reported in the test of the hypotheses.

Reliability. As already reported, Cronbach's alpha for the 20 item normalization measure is .86, demonstrating high internal consistency.

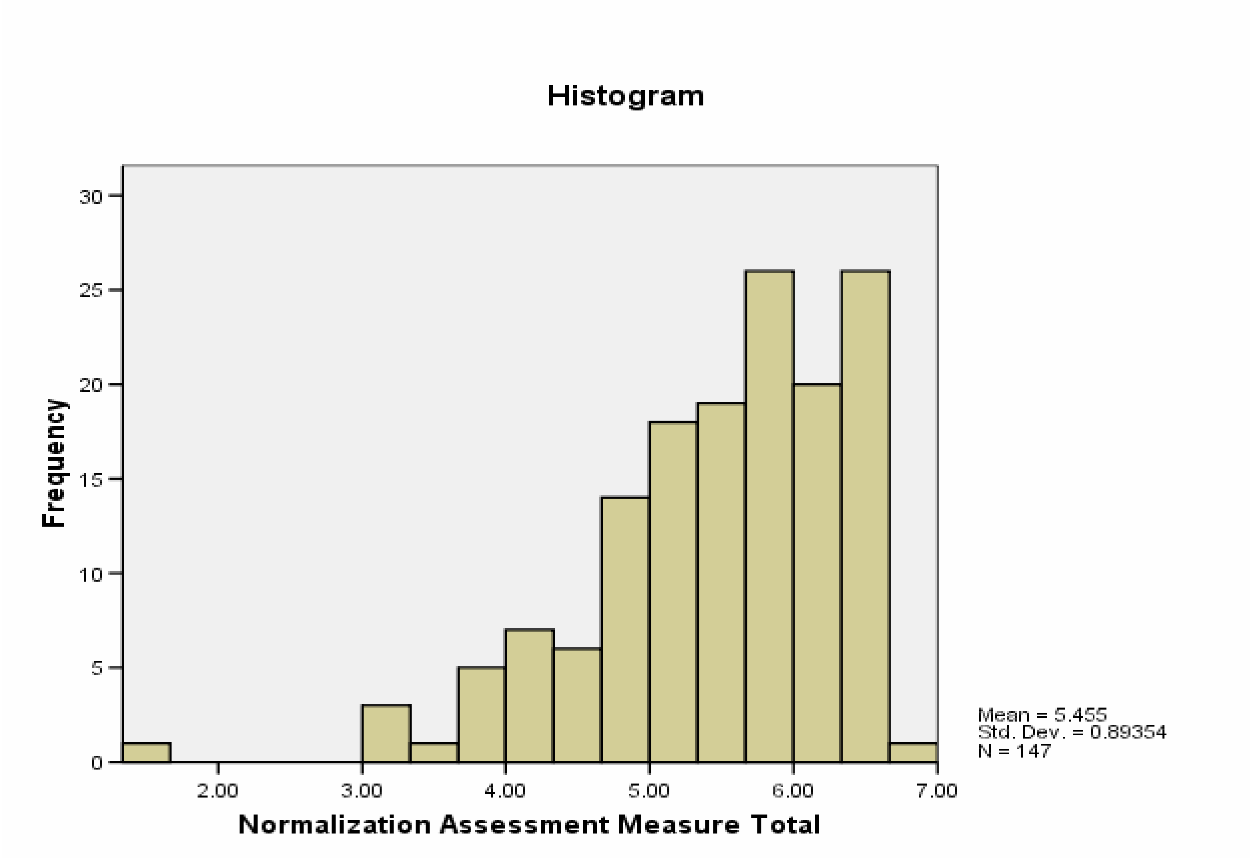

Figure 3: Histogram of the Normalization Assessment Measure

Table 3: Item Statistics

	Mean	Std. Deviation	Corrected Item Total Correlation	Cronbach's Alpha if Item Deleted
I am normal except for my condition.	6.19	1.54	.58	.84
I pace myself during the day in order to conserve energy.	5.49	1.81	.33	.85
I always maintain a normal appearance to others in the way I physically look.	6.18	1.40	.55	.85
I am better off than most people with my condition.	5.87	1.69	.57	.84
I have maintained social interactions with others despite my condition.	6.00	1.62	.74	.84
I live a normal life.	5.55	1.97	.65	.84
Everybody treats me normally.	6.01	1.51	.61	.84
There are worse things than being diagnosed with this illness.	6.65	1.09	.56	.85
I structure my activities to maintain normalcy.	6.07	1.52	.69	.84
I accept my condition.	6.25	1.42	.52	.85
I engage in activities such as exercise to feel normal.	4.92	2.02	.56	.84
I choose to skip more trivial activities so that I have the energy to participate in activities that I really value.	5.04	2.07	.44	.86
I'm like everyone else, everyone has to contend with something in life.	6.44	1.19	.36	.85
I maintain a normal appearance in the way I behave.	6.37	1.16	.66	.84
Keeping a routine is important to me.	5.90	1.70	.42	.85
I haven't changed the things I do since being diagnosed with this condition.	4.54	2.32	.63	.84
I try to hide any outward indications of my condition.	3.81	2.09	-.10	.87
I'm able to incorporate the treatment for my condition into my normal life activities.	5.09	1.85	.35	.85
I give excuses for any accidents in order to hide my condition.	2.96	1.80	.20	.86
I only tell those closest to me about my condition.	4.19	1.94	.04	.87

Table 4: Descriptive Statistics for Mean Item Scores

			Statistic	Std. Error
Normalization Assessment Measure Total	Mean		5.46	.07
	95% Confidence Interval for Mean	Lower Bound	5.31	
		Upper Bound	5.60	
	5% Trimmed Mean		5.50	
	Median		5.65	
	Variance		.80	
	Std. Deviation		.89	
	Minimum		1.35	
	Maximum		6.70	
	Range		5.35	
	Interquartile Range		1.30	
	Skewness		-1.23	.20
	Kurtosis		2.38	.40

Validity. The validity of the 20 item unidimensional normalization measure was tested by the following 12 hypotheses.

H1. Normalization and Problem Focused Coping. The first hypothesis stated that there would be a positive relationship between normalization and problem focused coping. The normalization measure correlated positively and significantly with the problem focused coping total score ($r = .56$, $p < .001$; $\rho = .53$, $p < .001$) as well as each of the subscales comprising problem focused coping except for the acceptance subscale where the low positive correlation was not significant (see Table 5 on the next page). Thus, hypothesis 1 is supported.

H2. Normalization and Emotion Focused Coping. The second hypothesis indicated that there would be a negative relationship between normalization and emotion focused coping. Normalization correlated negatively with the emotion focused coping total score ($r = -.32$, $p < .001$; $\rho = -.33$, $p < .001$). Behavioral disengagement was significantly correlated with normalization in the negative direction. However, the correlations for denial were not significant. The negative correlation of mental disengagement with normalization was not significant with parametric analysis but was significant with nonparametric analysis (see Table 5 on the next page). Therefore, there is support for the overall hypothesis.

Table 5: Correlations Between Normalization and Coping Measures

COPING INDICES AND SUBSCALES	**CORRELATIONS WITH NORMALIZATION MEASURE**
Problem Focused Coping Total Score	r = .56, p < .001 ρ = .53, p <.001
Acceptance subscale	r = .13, p > .05, ns ρ = -.01, p > .05, ns
Active Coping subscale	r = .49, p. < .001 ρ = .50, p < .001
Planning subscale	r = .60, p < .001 ρ = .59, p < .001
Positive Reinterpretation subscale	r = .26, p < .01 ρ = .25, p < .01
Suppression subscale	r = .47, p < .001 ρ = .56, p < .001
Emotion Focused Coping Total Score	r = -.32, p <.01 ρ = -.33, p <.001
Behavioral Disengagement subscale	r = -.41, p < .001 ρ = - .41, p < .001
Denial subscale	r = -.20, p < .05* ρ = -.13, p > .05, ns
Mental Disengagement subscale	r = -.15, p > .05, ns ρ = -.21, p = .01

* This is not significant at p < .01

<u>H3. Normalization and Sick Role Nonacceptance.</u> For hypothesis number three it was expected that the relationship between normalization and sick role nonacceptance would be positive. The normalization measure correlated positively and significantly (r = .26, p < .01; ρ = .38; p <.001) with the sick role nonacceptance score. Thus, hypothesis 3 is supported.

<u>H4. Normalization and Social Desirability.</u> For the fourth hypothesis, no correlation was expected between normalization and social desirability. The

correlation of social desirability with normalization was slightly positive but nonsignificant (r =.12; p >.15, ns; ρ =.13; p >.10). The hypothesis is supported.

H5. Normalization and the diagnosis of Fibromyalgia. Individuals with fibromyalgia were anticipated to score lower on the normalization measure than people without fibromyalgia, according to hypothesis number five. An independent samples t-test indicated that although the 20 individuals with fibromyalgia (M = 5.18) scored lower on the normalization measure than individuals with other diagnoses (M = 5.50), this difference was not statistically significant (t = 1.42; df = 145; p > .15, ns; Mann-Whitney U = 978.5, p > .10, ns). The hypothesis is not supported by these results.

H6. Normalization and Length of Time Since Diagnosis. Due to the trajectory of illness, it was theorized in hypothesis number six that a negative relationship would exist between length of time since diagnosis and normalization. For the sample as a whole, this relationship was nonsignificant (r = -.02, p > .75; ρ = .01, p > .85). This relationship was also examined separately within the four diagnostic categories. Normalization correlated negatively using the product moment correlation, but not significantly, with the number of years since diagnosis of rheumatoid arthritis (r = - .016, df = 77, p > .80; ρ = .07, p > .05), osteoarthritis (r = -.22, df = 35, p > .20; ρ = -.281, p > .05), and fibromyalgia (r = -.011, df = 19, p > .90; ρ = .03, p > .80). Normalization correlated positively, although again not significantly, with the number of years since the diagnosis of lupus (r = .29, df=16, p > .20; ρ = .29, p > .20). Additional analyses included the generation of scatterplots by diagnosis to examine possible curvilinear relationships. No relationships were identified. Thus, hypothesis 6 is not supported.

H7. Normalization and Perceived Control. Consistent with the conceptual framework, hypothesis seven predicts that perceived control will have a positive correlation with normalization. The perceived control index correlated positively with the normalization measure (r = .50, p <.001; ρ = .52, p < .001). In this study, helplessness correlated negatively with normalization (r = -.40, p < .001; ρ = - .36, p < .001). Perceived competence, as measured by the Perceived Medical Condition Self-Management Scale, correlated in a positive direction with normalization (r = .50, p < .001; ρ = .57, p < .001). Therefore, hypothesis 7 is supported.

H8. Normalization and Illness Intrusiveness. In hypothesis eight, a negative relationship was expected between normalization and illness intrusiveness. The normalization measure correlated significantly in the negative direction with the illness intrusiveness rating scale (r = -.59, p < .001; ρ = -.67, p < .001). Thus, hypothesis 8 is supported.

H9. Normalization and QOL. According to hypothesis number nine, there is a positive relationship between normalization and QOL. The QOL index correlated positively with the normalization measure ($r = .64$, $p < .001$; $\rho = .70$, $p < .001$). Looking at the separate components of QOL, normalization correlated positively with the life satisfaction scale ($r = .67$, $p < .001$; $\rho = .75$, $p< .001$) and with the positive affect PANAS subscale ($r = .18$, $p < .05$; $\rho = .16$, $p = .05$). Normalization correlated negatively with the MDHAQ subscale for difficulty in performing activities of daily living ($r = - .50$, $p < .001$; $\rho = - .52$, $p < .001$) and the negative affect PANAS subscale ($r = - .50$, $p < .001$; $\rho = - .63$, $p < .001$). Thus, these results support hypothesis 9.

<u>H9a. QOL as a function of Normalization, Perceived Control, and Illness Intrusiveness.</u> Hypothesis 9a posits that the variance in QOL is explained by the linear combination of perceived control, illness intrusiveness, and normalization. QOL correlated significantly with normalization ($r = .64$, $p < .001$; $\rho = .70$, $p < .001$), illness intrusiveness ($r = -.83$, $p < .001$; $\rho = -.82$, $p < .001$), and perceived control ($r = .78$, $p < .001$; $\rho = .77$, $p < .001$). A multiple linear regression analysis was performed using the perceived control index, normalization score, and illness intrusiveness as predictors of QOL. Seventy-eight percent of the variance in QOL was explained by normalization, perceived control, and illness intrusiveness ($F = 159.33$, $df = 3, 134$, $p < .001$). However, the tolerance scores for perceived control and illness intrusiveness in this three predictor regression model indicated a problem with multicolinearity. For this reason, the QOL index was regressed separately on normalization and perceived control omitting illness intrusiveness, and then again on normalization and illness intrusiveness omitting

perceived control. When perceived control is removed from the model, normalization and illness intrusiveness account for 73% of the variance in QOL (F = 184.90, df = 2,137, p < .001). When illness intrusiveness is removed from the model, normalization and perceived control predict 69% of the variance in QOL (F = 154.12, df = 2, 139, p < .001). Hypothesis 9a is supported.

H9b. Normalization Uniquely Explains Variance in QOL. Additionally, hypothesis 9b stated that, when controlling for illness intrusiveness and perceived control, normalization uniquely explains the variance in QOL. Normalization contributes 4% of unique variance in QOL in the model with illness intrusiveness as the other predictor and 9% of the unique variance in QOL in the model with perceived control as the other predictor. In both of these models, the amount of unique variance contributed by normalization is statistically significant at p < .001. Thus, hypothesis 9b is supported.

H10. Normalization and Social Ties. According to hypothesis number ten, there is a positive relationship between normalization and the presence of social ties. The presence of social ties correlated positively with normalization (r = .26, p < .01; ρ = .37, p < .001) although the magnitude of this correlation was much less than with other constructs examined in this study. Therefore, hypothesis 10 is supported.

H10a. Normalization and Social Ties, Perceived Control, Illness Intrusiveness. Hypothesis 10a stated that the variance in social ties is explained by the linear combination of perceived control, illness intrusiveness, and normalization. As stated earlier, a multicolinearity problem existed when all three predictors are included in the same model. Therefore, as with QOL, separate regression analyses were performed. First, the measure of social ties was regressed on illness intrusiveness and normalization. Those two predictors together accounted for 10% of the variance in social ties ($F = 7.65$, $df = 2, 139$, $p < .001$). A second multiple linear regression analysis indicated that perceived control and normalization predicted 8% of the variance in social ties ($F = 5.88$, $df = 2, 139$, $p < .01$). Thus, hypothesis 10a is supported.

H10b. Normalization Uniquely Explains Variance in Social Ties. Hypothesis 10b states that, when controlling for illness intrusiveness and perceived control, normalization uniquely explains the variance in social ties. Normalization contributed 1% of unique variance in explaining social ties in the model with illness intrusiveness as the other predictor and 4% of the unique variance explaining social ties in the model with perceived control as the other predictor. In neither of these analyses, however, is this significant amount of unique variance (at $p < .01$). Therefore, hypothesis 10b is not supported.

H11. Illness Intrusiveness as a Moderator. In hypothesis number 11, illness intrusiveness is predicted to moderate the relationship between normalization and QOL. In the first step of the hierarchical analysis, the main effects of normalization and illness intrusiveness explained 73% of the variance in QOL (F = 184.90, df = 2, 137; p < .001). In the second step of the analysis, the interaction of illness intrusiveness and normalization accounted for an additional 1% of the variance in QOL (F = 6.15, df = 1, 136, p < .01). Because the interaction term was significant, I was able to go on and examine the next two hypotheses, looking separately at those high and low in illness intrusiveness by a median split on that variable. Therefore, hypothesis 11 is supported.

H11a. High Illness Intrusiveness. I hypothesized that, among people with high illness intrusiveness, the relationship between normalization and QOL would be negative. However, the correlation between normalization and QOL in persons experiencing high illness intrusiveness was significantly positive (r = .60, p < .001). Therefore, hypothesis 11a is not supported.

H11b. Low Illness Intrusiveness. Among people with low illness intrusiveness, I hypothesized that the relationship between normalization and QOL would be positive. The correlation between normalization and QOL among individuals with low illness intrusiveness, was, indeed, positive but it was nonsignificant (r = .20, p < .05). Therefore, hypothesis 11b is not supported.

H12. Perceived Control as a Moderator. In hypothesis twelve, I expected that perceived control would moderate the relationship between normalization and quality of life. The main effects of normalization and perceived control explained 69% of the variance in QOL (F = 154.12, df = 2, 139, $p < .001$) in the first step of the hierarchical analysis. In the second step of the analysis, the interaction of perceived control with normalization explained 1% additional variance in QOL, but this was not a significant change in R^2 (F = 3.50, df = 1, 138, $p > .05$). Because the interaction term was not significant, this indicated that no moderation was present and, thus, I was not able to go on to examine the variance in quality of life as a function of high versus low perceived control. Therefore, hypothesis 12 is not supported.

CHAPTER V

DISCUSSION

The purpose of this study was to refine the normalization concept through the development of a measure suitable for use by researchers conducting quantitative research on how chronically ill individuals cope with their medical condition. Additionally, the intent of this study was to ascertain the psychometric properties of the normalization measure I developed using a sample of individuals diagnosed with rheumatogical conditions and, in doing so, advance our understanding of the role that normalization plays in these individuals' lives.

The two research questions for this project addressed the dimensionality and psychometric properties of the normalization measure that I developed. The instrument was initially envisioned as a 20-30 item unidimensional or multidimensional scale with a desirable alpha reliability (in the range of .80 to .90) as well as possessing content, discriminant, and construct validity. Consistent with this vision, the scale developed during the course of this study is a 20 item measure with an alpha reliability of .86 and is best described as unidimensional. A desirable alpha reliability between .80 and .90 can increase the statistical power of a scale, thus allowing fewer subjects to be sampled in order to detect significant differences (DeVellis, 1991). DeVellis recommends that scales with alpha reliabilities above .90 should be shortened, as scale length augments alpha reliability and scales with very high alphas most likely contain redundant items. The final (20-item) version of the normalization measure is an appropriate length resulting in decreased respondent burden with optimized internal consistency when compared to the original 36 item scale that had an alpha of .82.

Unidimensional scales assume that a single dimension exists influencing all of the respondents' answers on the same level. On the other hand, multidimensional scales allow for discrete differences between individuals to be assessed in terms of the various stimuli shaping an individual's response to an item (DeVellis, 1991; Nunnally & Bernstein, 1994). Earlier in this paper, normalization was conceptualized as having multiple dimensions. There are temporal aspects to normalization, perceptual (or cognitive) aspects to normalization, and behavioral aspects to normalization, thus creating a dynamic, cognitive-behavioral process. These aspects may be different dimensions of normalization. However, the items of the developed scale did not group together in identifiable subscales and, thus, I chose to treat the scale as a simple unidimensional summative scale. Perhaps with continued research, the multidimensionality of normalization may be tapped with items that group conceptually and mathematically together. In the meantime, treating the scale as unidimensional has led to a number of important findings that will be discussed below.

In this sample, the normalization scale scores were skewed negatively (to the high end) with a mean item score of 5.45 out of a possible 7.00, indicating that the majority of individuals normalized to a great extent. There are at least three reasons that the scores may be skewed negatively. First, it may be that the sample was heavily biased toward individuals diagnosed with conditions, such as osteoarthritis or rheumatoid arthritis, where individuals commonly normalize. Previous qualitative research has identified that individuals with arthritis employ normalization as a dominant mode of adaptation (Wiener, 1975; Robinson, 1993; Jerret, 1994). Individuals with lupus and fibromyalgia have not been studied previously in relationship to normalization. However, I hypothesized that individuals with fibromyalgia would be less likely to normalize because these individuals are often engaged in sick role behavior in order to convince others they are not well. The mean normalization score for individuals with fibromyalgia was lower than for the other diagnoses studied, although the difference was not significant. There were, however, only 21 individuals (13 % of the total sample) diagnosed with fibromyalgia. It may be that due to the small percentage of individuals with fibromyalgia in my sample, there was not enough power to detect significant differences in normalization between those who were diagnosed with fibromyalgia and those who were not. Clearly, though, even individuals with fibromyalgia scored higher on the normalization scale than I had expected.

Second, it may be that individuals who were normalizing to a greater extent were predisposed to participate in the study as a result of their increased satisfaction with life. Individuals who were less positive about their life may have been less positive about the opportunity to participate in survey research, particularly research delving into coping with chronic illness. Dillman (2000) identifies that a positive impression is created when a survey is highly salient, is easy to do or has little perceived cost, and looks interesting and important or is rewarding to complete**.** Individuals who are depressed may not view a survey about coping as rewarding to fill out. In fact, one potential participant contacted this researcher after receiving the questionnaires and refused to complete the survey. She stated, “I am having great difficulty coping with this disease and I’m afraid I would throw off your results because I’m so depressed.”

Third, the normalization measure may have inherent biases. The items may be worded in such a way as to create a bias toward the high end of the response scale or the measure may not be sensitive enough to discriminate and detect individual differences all along the continuum of normalization. Mean item scores on the normalization measure ranged from 1.35 to 6.70 on a 7 point scale. We would expect that if the scale did not discriminate individual differences that such a range of scores would not exist. Additionally, we would not expect the strong correlations obtained between the normalization measure and the various other scales I administered if the normalization scale failed to detect differences. Therefore, even with a bias toward agreeing with the normalization items, there is sufficient variation in item responses to see moderate to strong correlations with other theoretically related measures.

Despite the fact that the 20 item unidimensional normalization measure I have developed is internally consistent with an alpha of .86, I have only so far established one type of reliability for this new tool. Another type of reliability is test-retest reliability which assumes temporal stability of the measure as well as the underlying construct (DeVellis, 1991). For normalization, the question of temporal and construct stability has yet to be answered and leads to the question of whether normalization is best viewed as a state or trait. An antecedent to normalization, as discussed in Chapter Two, is the desire for normalcy. This desire could be conceptualized as a trait predisposing individuals to normalize. On the contrary, one might argue that just because an individual is diagnosed with a chronic manageable condition and may choose to normalize in that specific circumstance, if the same individual is diagnosed with a different condition, cognitive and perceptual differences may result in the individual opting to adapt in a different manner. Certainly, the idea that individuals “choose” their adaptation mode may be more closely associated with a state versus trait premise. Nonetheless, the establishment of test-retest stability would contribute additional evidence for the reliability of the measure. One would expect that in the absence of situational changes, a high correlation between normalization scores would exist when the measure was administered on two separate occasions within a short period of time.

The normalization measure has some content validity. Content validity was established using the existing literature about normalization and input from experts in the fields of normalization, coping, and instrument development during Phase One. In light of the unidimensionality of the measure and the lack of correlation with acceptance and denial subscales, further work might be necessary to expand the content validity of the scale.

Construct Validity

Construct validity (including convergent and discriminant validity) was established by examining twelve specific hypotheses most of which were supported by the data gathered during Phase Two. Convergent validity was demonstrated by comparing selected subscales of the COPE and a measure of sick role nonacceptance with the normalization scale. As expected, there was a positive correlation between the problem focused coping index I constructed and the normalization scores. Also, there were significant positive correlations between normalization and the following subscales of the COPE: planning; suppression of competing activities, positive reinterpretation, and active coping. This is consistent with the premise that normalization involves voluntary responses comprised of engagement coping strategies as discussed earlier in Chapter Two.

Normalization did not correlate significantly with acceptance, one of the COPE subscales I included in my index of problem focused coping. This may be due to a lack of items in the normalization measure eliciting the concept of acceptance. The normalization measure has one item related to acceptance on which individuals averaged a score of 6.25. On the other hand, the acceptance subscale for the COPE mainly assesses finality and perceived inability to "change what has happened." A clear foundation of normalization is that individuals acknowledge the presence as well as the seriousness of the condition (Hilton, 1996; Knafl & Deatrick, 1986). This researcher equated acknowledgement with acceptance. Although individuals may acknowledge having the condition, it may be that individuals do not equate acknowledgement with acceptance. Acceptance may be viewed more from the aspect of "giving into" the illness which, in fact, is contrary to incorporating the condition into one's life as is true with normalization.

Normalization correlated negatively, as anticipated, with the emotion focused coping index. For the subscales of the emotion focused coping index, normalization correlated negatively and significantly with mental disengagement and behavioral disengagement. The significant correlation with mental disengagement is clearly borderline, given that the rank-order correlation was significant at p = .01 but the product-moment correlation was not. The significant negative correlation with behavioral disengagement was expected. The coping strategies of normalization include some behavioral disengagement tactics such as selective association with chronically ill others. The negative relationship with denial was also expected, but was not significant. Denial, a subscale of the COPE that was included in my emotion focused coping index, is thought of as the polar opposite of acceptance. The findings that both the acceptance subscale and the denial subscale of the COPE were uncorrelated with the normalization measure give some credence to the notion that additional content validity might be needed for the normalization measure. Or, it may indicate that more work needs to be done with the conceptual framework undergirding normalization. An alternative explanation is that the acceptance and denial subscales of the COPE may not validly measure acceptance and denial.

The sick role nonacceptance score was also utilized to establish the convergent validity of the normalization measure. The sick role nonacceptance score correlated positively with normalization, as anticipated, but the magnitude of this correlation indicated that the two scores share only around 10% common variance. The size of the correlation could possibly have been affected by the method I used to derive the sick role nonacceptance scores. Although squaring the differences between self ratings and ratings of “the average person who is sick” is a defendable way of creating a distance score, I acknowledge that other ways of calculating the sick role nonacceptance score might have resulted in somewhat different findings. Clearly, however, in spite of the unexpected null results between normalization and the acceptance and denial subscales of the COPE, the results discussed thus far support the convergent validity of the new normalization measure by showing its relationship to validated measures of similar constructs.

Hypotheses seven through twelve identify expected relationships between normalization and other constructs based on the conceptual framework described earlier in Chapter Two. In hypothesis seven, eight, and nine, it was posited that normalization would correlate with perceived control, illness intrusiveness, social ties and quality of life. Indeed, the normalization measure correlated substantially with the perceived control index, the illness intrusiveness rating scale, and the quality of life index. Higher normalization scores correlated with higher perceived control scores, greater quality of life scores, and lower illness intrusiveness scores. These relationships are consistent with the conceptual framework linking the concepts. The relationship of high normalization scores with high quality of life scores supports the contention that normalization is a positive, desirable mode of adaptation.

Additionally, a subproposition of hypothesis nine stated that quality of life could be predicted by a linear combination of perceived control, normalization, and illness intrusiveness. Although this subproposition did not directly speak to the validity of the normalization measure, it was included because it speaks to the significance of normalization and gives support for the further investigation of the contradictory outcomes of normalization. Testing this proposition was difficult in light of the multicolinearity issues among the predictors, particularly including both perceived control and illness intrusiveness in the same equation. Thus, normalization was coupled separately with perceived control and illness intrusiveness, with each model significantly accounting for variance in QOL. QOL is influenced by a combination of normalization and illness intrusiveness as well as the combination of normalization and perceived control. The significant Rsquares in each of these models, however, merely demonstrate that the normalization measure works in conjunction with either perceived control or illness intrusiveness to predict QOL; in and of itself, the fact that hypothesis 9a was supported is a weak argument for the validity of the normalization measure.

However, another subproposition of hypothesis nine predicted that normalization would uniquely contribute to the variance in QOL when controlling for perceived control and illness intrusiveness. Normalization did significantly contribute uniquely to the variance of QOL as expected. Normalization uniquely accounted for 4% of the variance in QOL when paired with illness intrusiveness and 9% of the variance in QOL when paired with perceived control. The performance of the normalization measure in explaining QOL when controlling for other relevant concepts from the conceptual framework is strong support for the construct validity of the normalization measure I developed.

The QOL index was constructed by weighting life satisfaction score three times the other measures for QOL. The measurement of QOL is widely debated in the literature. Early conceptualizations placed emphasis on subjective measures of satisfaction or happiness. However, QOL is multifaceted and mere measures of satisfaction or happiness do not accurately reflect the broad scope of QOL. For this reason, the QOL index for this study included physical, affective and life satisfaction components. Life satisfaction is considered to be the cognitive or appraisal component of QOL and does tend to be a relatively stable variable (Nes et al). Individuals tend to base their evaluation of life satisfaction on standards they set for themselves. This standard often depends upon health and energy as well as other factors. The weights associated with these factors will differ across individuals (Tate & Forchheimer). Thus, it seems that while physical functioning impacts QOL, the influence of overall life satisfaction may override some of the impact of physical functioning. Therefore, life satisfaction was weighted more than physical functioning. This weighting of life satisfaction may have contributed to the findings supporting the hypothesis. However, the correlation is highly significant and it may be argued that even without the weighting of life satisfaction, significant results would have been obtained.

Hypothesis ten examined the relationship between normalization and social ties. The maintenance of social ties is often a priority for individuals and families who normalize (Dewis, 1989; Rehm & Franck, 2000). Additionally, the literature supports the idea that families who normalize with ease describe having social support. For this reason, a positive correlation was anticipated between normalization and social ties. Indeed a significant positive relationship, albeit a modest one, was demonstrated between normalization and social ties. Thus, the presence of a social network correlated positively with more normalization. While a positive relationship exists, it remains to be determined whether individuals normalize more easily in the presence of an extensive social network or whether the process of normalization assists the individual in maintaining social ties or both. The conceptual framework identifies social support as an influencing factor for normalization and the maintenance of social ties as an outcome of normalization. The measure utilized was a 3-item measure assessing social network in terms of the number of close friends, the number of close family and the number of known people who understand the individual's condition. This measure does not reflect the *maintenance* of social ties and, thus, does not yield enough information about the social support given to or felt by the ill individual. In order to truly assess the maintenance of social ties, a longitudinal study would have to be conducted or at the very least, retrospective self report information about the individual's social network pre-diagnosis as well as post diagnosis would need to be obtained.

Hypotheses eleven and twelve posed expectations about potential moderators of normalization as an explanation for some of the contradictory outcomes in quality of life and social ties that had been reported in the literature. In hypothesis eleven, illness intrusiveness was hypothesized to moderate the relationship between normalization and quality of life. Based upon previous research findings, I surmised that the more intrusive a condition or its treatments, the more energy an individual would expend in normalization efforts which, in turn, may actually lead to a decreased quality of life. In essence, I felt that positive quality of life occurs when individuals can easily incorporate an illness or condition into their everyday life with minimal intrusion. The results, however, indicate that the relationship between normalization and quality of life was positive for both individuals with high illness intrusiveness and those with low illness intrusiveness. In fact, the positive relationship was significant for high illness intrusiveness, where I expected a negative relationship, and nonsignificant for low illness intrusiveness. Thus, individuals in my sample who successfully normalize in spite of the effort expended to overcome the intrusiveness of the illness, report a positive quality of life. Perhaps this is a reflection of personal satisfaction for a goal obtained, particularly given the weight attributed to life satisfaction in the quality of life index. Another possibility is that the scale chosen as a measure illness intrusiveness may not measure disease intrusiveness. This possibility is unlikely because the measure utilized has demonstrated high reliability and validity in other studies. More research will need to be conducted to determine the variables affecting decreased quality of life amongst individuals who normalize. A possible answer may be that illness trajectory would affect normalization efforts and quality of life. As the trajectory of an illness leads to more intrusive symptoms or effects, normalization efforts may be ineffective despite the energy expended and thus result in a lowered quality of life.

In hypothesis twelve, it was posited that perceived control would moderate the relationship between normalization and quality of life. However, a moderational relationship was not supported by the results in this study. There is a positive correlational relationship between perceived control and normalization. It may be that perceived control is essential for normalization to occur. Individuals may not be able to employ the cognitive and behavioral strategies necessary for normalization unless they perceive control over their behavior, situation and appearance. Thus, it may be that normalization mediates the relationship between perceived control and quality of life. This could be a possible future area of research.

Hypothesis number six addressed the length of time since diagnosis and normalization as a way to examine illness trajectory. Theoretically, for most chronic illnesses, a longer time since diagnosis corresponds to the development of more severe symptoms or complications as a result of the illness or the treatment or both. The expectation was that there would be a negative relationship between normalization and length of time since diagnosis. All of the relationships between length of time since diagnosis and the various conditions (OA, RA, Lupus and Fibromyalgia) were nonsignificant. The relationships varied in terms of positive and negative directions, even within a diagnosis based on whether the product moment correlation or the rank order correlation was calculated. The results are unclear, most probably as a result of the way in which the data were obtained and coded. Participants self-reported their diagnoses and, in some cases, participants reported more than one diagnosis of interest (i.e., arthritis and fibromyalgia, or arthritis and lupus). For this sample, the majority of individuals had been diagnosed for less than 10-15 years. It may be that modern advances have reduced the trajectory of rheumatoid illnesses where differences related to trajectory would be detected in individuals diagnosed for longer periods of time. More research is needed to better isolate differences amongst conditions in relationship to normalization as well as differences related to length of time since diagnosis.

Discriminant Validity

In this study, discriminant validity of the new normalization scale was established using the shortened measure of social desirability bias advocated by Strahan & Gerbasi (1972). No relationship was expected between social desirability and normalization, and none was found. The normalization measure is distinctly different from social desirability as evidenced by the lack of any correlation between the two measures. The low alpha reliability for the 10-item social desirability measure in this study is a concern. While the alpha reliability is low in my study for this social desirability measure, the normalization score does not correlate with the underlying concept that constitutes the Strahan and Gerbasi (1978) social desirability measure. Thus, in that sense, I am confident that discriminant validity of my normalization scale has been demonstrated.

In summary, validity of the normalization assessment measure was established in the following ways. Content and face validity of the new normalization measure was established from feedback obtained from participants in phase one of the study and from feedback of the expert panel during development of the normalization instrument. Convergent validity was examined in Phase Two through the use of one or more coping measures and the Sick-Role Acceptance Scale. Additionally, construct validity was supported through the examination of normalization in relationship to the identified influences (perceived control, illness intrusiveness) and outcomes (quality of life, maintenance of social ties) of normalization as set fourth in my conceptual framework (see Figure 1 on page 21) . Discriminant validity is another subcomponent of construct validity. In this study, discriminant validity was established using a shortened measure of social desirability bias. While this study has been a good start, it is acknowledged that much more work could be done to establish the construct validity of this new instrument.

Threats to Statistical Validity

Threats to statistical validity have been minimized in this study through the following strategies. Sample size was adequate enough to detect an effect. The other measures utilized in Phase Two were reliable and presumed valid. Subject burden for completing measures was considered. The number of measures and the number of items used was limited when appropriate to minimize subject burden with completion of forms. Multiple measures of perceived control and quality of life and multiple subscales of problem and emotion focused coping were used to increase the validity of these constructs.

Limitations

All of the data collected for this study was through self-reports using mailed questionnaires. Mailed questionnaires offered several advantages and disadvantages. The advantages of a mailed survey were: (1) a more representative sample of individuals with varied levels of disability (the mailing included individuals who were not frequently seen in the physician's office); (2) the attainment of a greater number of subjects within a smaller amount of time; (3) individuals had privacy for completing questionnaires; and (4) individuals were under no time constraints to complete the questionnaires within one sitting.

In terms of disadvantages, mailed questionnaires had the following drawbacks: (1) the questionnaires had to stand alone without needing clarification by the researcher; (2) the researcher had no control of environmental influences; (3) the researcher had no control over who chose to respond versus who chose not to respond; and (4) response rates were lower than desired (Bourque & Fielder, 1995).

Several strategies were employed to counter the disadvantages of mailed questionnaires. The number of questionnaires within the packet was limited to minimize participants feeling overwhelmed. The questionnaires were organized in a user-friendly manner with a generous amount of white space so as not to seem too complex and cumbersome. The instructions were clear and concise. An addressed, stamped return envelope was included to minimize subject burden for returning the questionnaires. A reminder postcard and thank you card was mailed several weeks after the questionnaire.

Even with the tactics employed to ensure an optimum response rate, the data collection portion of the study took much longer than anticipated. Potential participants for the focus groups were difficult to recruit as many individuals lived in households with no car or only one car and, perhaps, clustered their errands with physician appointments. Additionally, participants preferred the option of participating in Phase Two instead of Phase One. The delay in completing Phase One created a time lag between the initial contact for recruiting participants for Phase Two and the actual mailing of the questionnaires. Reminder calls were placed just prior to the mailing of the questionnaires to confirm address information. However, some of the participants who had initially agreed to be involved in Phase Two no longer were accessible at the phone number or address on record. In retrospect, it may have been expedient to have recruited for Phase One directly in the physician's office and hold an impromptu focus group with patients awaiting their physician appointment.

Another limitation of this study was the design method utilized. A cross-sectional design allows for the examination of variables at one point in time and can be a convenient method of gathering data. However, in order to really be able to determine causal relationships, a longitudinal study is more appropriate.

Additionally, the individuals sampled included only those with rheumatological conditions. Normalization is universal across disease entities; however, for the ease of data collection, four conditions within one specialty area were chosen. Although all of the individuals were diagnosed with a rheumatological disease, I tried to strengthen the generalizability of my results by including four separate conditions to ensure variability of responses and levels of disability.

Future Research

Further development of the normalization measure may be necessary. Future development should focus on enhancing content validity with particular attention to be paid to the possible multidimensionality of normalization. Also, as mentioned under Limitations, this study only examined normalization in persons diagnosed with a rheumatological condition. The measure I developed will need further refining and testing with other populations, such as patients with multiple sclerosis or diabetes, to increase external validity and generalizability.

Conclusion

This study has refined the concept of normalization through the development of an assessment measure, thus giving researchers the alternative of using quantitative methods to investigate and clarify some of the contradictory outcomes associated with normalization. This measure will enable researchers to determine under what conditions does normalization result in: (1) increased quality of life rather than a decrease; (2) increased resource utilization rather than a decrease in accessing resources; and (3) increased adherence to treatment regimens rather than noncompliance with the recommendations of healthcare professionals. Once more information is known about the conditions under which normalization leads to optimum outcomes, nurses will be able to promote and foster an individual's need for normalcy, consistent with the role of nursing in Orem’s (1995) theory of self-care agency. This measure, while early in its infancy and, perhaps, in need of further development, is internally consistent, apparently valid, and reasonable efficient.

Additionally, this study was able to report some important findings about normalization and quality of life, thus strengthening the conceptual framework. Clearly, normalization does contribute to a positive quality of life. This contribution occurs in conjunction with either illness intrusiveness or perceived control. Findings from this study indicate that moderational effects were not present for illness intrusiveness or perceived control so the nature of the relationship between normalization, perceived control, illness intrusiveness and quality of life will need further investigation. However, the confirmation of a relationship between normalization and these variables is an important first step.

APPENDIX A: Studies of Normalization from the Chronic Illness Perspective

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
1. Schwartz (1957)	Not addressed/ Interviews/ Not addressed	20 wives with psychotic husbands	Wives characterized their husbands' behavior from a normalcy framework	No measures addressed	Limited characteristics of the sample	No measures addressed	Findings linked to examples from the data
2. Davis (1961)	Not addressed/ Interviews/ Not addressed	16 visibly handicapped individuals	Individuals redefine self attributes to identify themselves as normal or similar to others	No measures addressed	Limited characteristics of the sample	No measures addressed	Findings linked to examples from the data
3. Wiener (1975)	Grounded Theory/ Observation and interviews/ Constant comparative analysis	21 individuals with arthritis	Strategies arthritics develop in order to tolerate uncertainty	Interviews and observation	Findings linked to other research	No measures addressed	Findings linked to examples from the data
4. Miles (1979)	Exploratory/ Semi-structured interviews/ Not addressed	22 individuals with multiple sclerosis and their spouses	Characteristics of couples who normalize versus couples who dissociate	Data presented is linked to coding categories	No measures addressed	No measures addressed	Findings linked to examples from the data
5. Krulik (1980)	Not addressed/ Structured interview/Not addressed	20 chronically ill children and their mothers; 20 healthy children and their mothers	Normalizing tactics	Data presented is linked to coding categories	Limited characteristics of the sample described	No measures addressed	Findings are linked to examples from the data
6. Anderson (1981)	Ethnographic/ Participant-Observation (3 visits)/ Not addressed	4 families with chronically ill children (leukemia and diabetes) & 12 families with well children	Double bind communication results from inconsistencies between the way parents view their child and the illness and the way the child is treated	Interviews and observation	No measures addressed	No measures addressed	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
7. Anderson & Chung (1982)	Ethnographic/ Participant-Observation (3 visits)/ Not addressed	7 families with a child experiencing a long term medical problem	Construction of the illness experience	Interviews and observation	Findings linked to other research	No measures addressed	Findings linked to examples from the data
8. Anderson (1986)	Comparative; Phenomenology/ 3-4 In-depth taped interviews; Observation/ Not addressed	6 Chinese and 7 Anglo-Canadian families of a chronically ill child	Normalization is consistent with Western approach to health and may not match the priorities of other cultural groups	Member checking; Peer debriefing; Interviews and observation	Findings linked to other research	Peer review	Member checking; Findings linked to examples from the data
9. Gerhardt & Brieskorn-Zinke (1986)	Not addressed/ 2 taped intensive interviews 1 year apart/ Not addressed	68 individuals with end-stage renal failure and their spouses	Normalization is a process of mastery	Interviews 1 year apart	No measures addressed	No measures addressed	Findings linked to examples from the data
10. Mishel & Murdaugh (1987)	Grounded Theory/ Audiotaped data entered by researchers after support group meetings/ Constant comparative analysis	20 family members of individuals undergoing heart transplantation	Family adjustment to heart transplantation included redesigning the dream to meet the challenge of unpredictability through immersion, passage and negotiation	Data gathered over 2 1/2 years; Observation; Peer debriefing; Triangulation Member checking	Descriptions provided; Observation; Limitations addressed; Peer debriefing	Audit trail; Peer review	Member checking; Peer review

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
11. Deatrick (1988)	Not addressed/ Open-ended taped semi-structured interviews/ Classified as normalizers and nonnormalizers	15 parents of children with osteogenesis imperfecta	Behavioral strategies used by parents to achieve normalization	Peer debriefing	Description of sample	No measures addressed	Findings linked to examples from the data
12. Anderson Elfert & Lai (1989)	Phenomenology/ 3 Semi-structured audiotaped interviews/ Constant comparative analysis	15 Chinese and 15 Anglo-Canadian families with chronically ill children	The goal of normalization is a western ideal Material circumstance may influence the ability to normalize	3 interviews; Multiple researchers; Peer debriefing	No measures addressed	Data protocols used by all researchers; Peer review	Findings linked to examples from the data
13. Dewis (1989)	Descriptive/ One in-depth audiotaped semi-structured interview/ Content analysis	15 young people with spinal cord injury	Efforts to normalize include: physical appearance and function, physical and emotional independence, and social skills and interpersonal relationships	Peer debriefing	Findings linked to other research	Peer review; Coding checks for consistency	Findings linked to examples from the data
14. Bossert, Holaday, Harkins & Turner-Henson (1990)	Not addressed/ Parental and child Interviews/ Theoretical coding	365 chronically ill children age 10-12 years	Normalization strategies pertaining to child and family life	No measures addressed	Findings linked to other research	Consensus of coding	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
15. Elfert, Anderson & Lai (1991)	Phenomenology/ Unstructured taped in-depth interviews/ Constant comparison analysis	16 Chinese families and 15 Euro-Canandian families with a chronically ill child	Parental perceptions of a child's illness	Member checking	Findings linked to other research	Consensus of coding	Member checking; Findings linked to examples from the data
16. Gagliardi (1991)	Ethnography; naturalistic case study/ In-depth taped interviews and participant-observation over a 10 week period/ Constant comparative analysis	3 families with a child experiencing Duchenne muscular dystrophy	Six themes of families living with an ill child	Bias log kept; Triangulation Member checking; Peer debriefing	No measures addressed	External coding auditors; Peer review	Member checking
17. Gagliardi (1991)	Ethnography; naturalistic case study/ In depth taped interviews and participant-observation over a 10 week period/ Constant comparative analysis	3 families with a child experiencing Duchenne muscular dystrophy	Six themes of families living with an ill child	Triangulation Member checking; Peer debriefing	Description of sample	External coding auditors; Peer review	Member checking
18. Keller (1991)	Grounded Theory/ 10 unstructured audiotaped interactive interviews/ Constant comparative analysis	8 men and 1 woman who underwent Coronary Artery Bypass Graft Surgery	3 stages of seeking normalcy after surgery: surviving, restoring and being fixed	Member checking; Peer debriefing	Findings linked to one other study	Audit trail; Peer review	Member checking; Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
19. Sawyer (1992)	Pre-Experimental, static grouup comparison design/ Feetham Family Functioning Survey; Family Profile Inventory	64 mother-child dyads where the child was diagnosed with cystic fibrosis	Perceptions of family functioning did not differ between group with ill child vs group without ill child				
20. Whyte (1992)	Ethnography; Exploratory; Case study; Life History/ Multiple interviews; Activities of Living Model; In-depth taped interview/ Constant comparative analysis	4 families caring for a child with cystic fibrosis	The experience of caring for a child with cystic fibrosis and its effect on family interaction	Data collected over multiple points in time	Findings linked to other research	No measures addressed	Findings linked to examples from the data
21. Dashiff (1993)	Descriptive/ One time structured audiotaped interviews of each parent/ Concept book analysis	12 parental couples & adolescent daughters with diabetes	Parental perceptions: drawing the family closer; minimizing the negative impact on daughters; sacrificing the spousal relationship and heightening parental roles; suffering emotional distress in the parental role; managing emotional distress through overseeing distancing, communicating and receiving and accessing support	Member checking with 7 respondents	Findings linked to previous research	No measures addressed	Member checking; Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
22. Ray & Ritchie (1993)	Audiotaped semi-structured interview; CHIP; COBI/ Content analysis	29 parents of an ill child	Influences of parental coping	Method triangulation	Findings linked to previous research	Interrater reliability assessed for consistency of coding	Findings linked to examples from the data
23. Robinson (1993)	Grounded Theory/ Repeated in-depth interviews/ Open coding, Axial coding, Selective coping, and Constant comparative analysis	40 men and women experiencing spina bifida, muscular dystrophy, asthma, allergies, multiple sclerosis, arthritic, back problems, heart disease and inflammatory bowel disease	Managing chronic illness while constructing life as normal: the process and benefits and costs	Data collected over multiple points in time	Findings linked to other research	No measures addressed	Findings linked to examples from the data
24. Ferrell, Rhiner, Shapiro & Dierkes (1994)	Phenomenology/ Structured tape recorded interviews; FPS/ Content analysis	31 parents of a child with cancer pain	Impact of pain on the family	Peer debriefing	Description of sample	Peer review	Findings are linked to examples from the data
25. Haase (1994)	Phenomenology/ Audiotaped open-ended structured interview/ Step by step described by Colaizzi	7 Children with cancer	Six theme categories were identified among children who had completed cancer therapy	Member checking; Peer debriefing	Description of sample	Coding checks	Member checking; Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
26. Jerret (1994)	Phenomenology/ Interviews/ Interpretive analysis	19 parents from 10 families of a child with juvenile arthritis	Experience of learning to care for a chronically ill child	Member checking	Findings linked to other research	Peer review	Member checking; Findings linked to examples from the data
28. Edwards-Beckett & Cedargren (1995)	Qualitative/ Audiotaped semistructured interviews/ Content analysis	27 fathers and 30 mothers of a child with myelomeningocele	Sociocultural context of different types of family management styles	More than one coder; Peer debriefing	Description of sample; Findings linked to other research	Coding checks	Findings linked to examples from the data
29. Knafl et al. (1995)	Grounded Theory/ Audiotaped semi-structured interviews/ Narrative analysis; Constant comparative analysis	63 families with a chronically ill child	Themes in events preceding diagnosis	Peer debriefing	No measures addressed	Peer review	Findings linked to examples from the data
30. Royer (1995)	Grounded Theory/ Open-ended in-depth interview/ Inductive analysis	35 men and women diagnosed with a chronic illness	Six behavioral and seven cognitive normalization strategies used to counteract the difficulties caused by chronic illness	No measures addressed	No measures addressed	No measures addressed	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
31. Williams (1995)	Exploratory/ One time semi-structured audiotaped interviews/ Constant comparative analysis	12 mothers of daughters with precocious puberty or Turner syndrome	Maternal management of problems encountered during school, with peers and at home	Peer debriefing	Linked to one other research study	Peer review	No measures addressed
32. Hilton (1996)	Grounded Theory/ 5 semi-structured audiotaped interviews/ Constant comparative analysis	55 women with early stage breast cancer and members of their family	Strategies for getting back to normal included: seeing their families as normal, minimizing disruptions, deemphasizing sick role demands, reframing negatives and putting the cancer behind; Influences on the process	5 interviews over 1year; More than 1 researcher; Member checking	Linked to other research	Audit trail	Member checking; Findings linked to examples from the data
33. Jerret & Costello (1996)	Grounded Theory/ Semi-structured audiotaped interviews over 2 years/ Open coding, axial coding, selective coding and constant comparative analysis	30 mother and 9 fathers from 30 families where a child was diagnosed with asthma	3 phases for accommodating to child's illness: being out of control, being involved, and being in control	Interviews conducted over 2 year period; Peer debriefing; Data linked to coding categories	Description of sample; Linked to other research	Peer review	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
34. Knafl et al. (1996)	Naturalistic/ 2 Audiotaped open ended semi-structured interviews with parents, ill children and siblings conducted 12 months apart/ Inductive content analysis	63 families where a child was chronically ill	Description of family management styles	Interviews conducted 12 months apart; More than one investigator	Description of sample	No measures addressed	Findings linked to examples from the data
35. Thorne et al. (1997)	Interpretist, Naturalistic approach/ Interviews/ Constant comparative analysis	16 nurses 7 parents of children with long term gastrostomy	The meanings of gastrostomy to parents and health care professionals	Multiple people interviewed about same topic; More than one researcher	No measures addressed	No measures addressed	Findings linked to examples from the data
36. Clarke-Steffen (1997)	Grounded Theory/ 3 semi-structured audiotaped interviews/ Constant comparative analysis	7 mothers, 7 fathers, 6 ill children, 12 siblings from 7 families with a child experiencing cancer	Families used 6 strategies to create a new normal routine as they adapted to the diagnosis of childhood cancer	Member checking with 2 families	Description of sample; Findings linked to other research	No measures addressed	Member checking

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
37. Gravelle (1997)	Phenomenology/ Audiotaped interviews (1st interview unstructured and 2nd interview semi-structured/ Giorgi's steps for data analysis	11 parents of an ill child (Duchenne muscular dystrophy, spinal muscual atrophy type II; metachromatic leukodystrophy, Retts syndrome, cerebral palsy with microcephay and respiratory distress	Process of facing adversity	Member checking; Data collected on 2 occasions	Findings linked to other research	No measures addressed	Member checking; Findings linked to examples from the data
39.Murdaugh (1998)	Grounded theory/Open-ended audiotaped interviews/Constant comparative analysis	14 adults diagnosed with HIV	Adjustment to HIV through achieving a balance (4 stages)	Multiple interviews; Peer debriefing; Member checking	Description of sample	Peer review	Findings linked to examples from the data
40. Stubblefield & Murray (1998)	Phenomenology/ Unstructured audiotaped interviews/Colaizzi method	15 parents of 12 children who have undergone lung transplantation	Parental perceptions of living with children who have undergone lung transplantation	Multiple interviews; Peer debriefing, Member checking	Description of sample	Audit trail	Findings linked to examples from the data; Member checking
41.Tishelman & Sachs (1998)	Exploratory/ Semi-structured interviews/ Constant comparative analysis	46 persons with cancer	Persons first become "nonnormal" before they become "normally diseased"; redesigning the concept of normality	Member checking; Peer debriefing	Findings linked to other research	Peer review	Member checking; Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
42.Seppanen (1999)	Case study/ Interviews and observation over 4 separate periods/ Time series and content analysis	2 sets of parents of 2 girls (age 3 and 4) diagnosed with diabetes	Six phases of the parental coping process: disbelief, lack of information and guilt, learning of care, normalization, uncertainty and reorganization	Interviews and observation/ Data gathered at multiple points in time/ Member checking	Findings linked to other research	Not addressed	Findings linked to examples from the data/ Member checking
43. Witte & de Ridder (1999)	Not addressed/ Support group sessions/ Not addressed	5 children aged 9-13 with HIV infected mothers	Coping strategies	Not addressed	Not addressed	Not addressed	Not addressed
44. Hilton, Crawford & Tarko (2000)	Qualitative Participatory Action/ Audiotaped semi-structured interviews/ Open coding; Constant comparative analysis	10 spouses with wives diagnosed with breast cancer	Men's ways of coping: focusing on wife's illness and care and focusing on family to keep life going.	Peer debriefing	Description of sample	Audit trail; Peer review	Findings linked to examples from the data
45. Johnson (2000)	Grounded Theory/ Audiotaped structured telephone interviews/ Constant comparative analysis	Mothers of preschool and elementary school-age children with mild to moderate physical disability	Parental straddling on 3 levels: past vs present, child as normal vs disabled, child vs parent feelings and issues	Not addressed	Findings linked to other research	Not addressed	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
46. Morse, Wilson & Penrod (2000)	Not addressed/ Participant observation; Audiotaped interviews/Content analysis	17 children with chronic, severe, life-threatening physical disabilities at a 6 day camp	The disabled child's process of normalizing when away from family	Observation and interviews	Description of sample	Not addressed	Findings linked to examples from the data
47. Rehm & Franck (2000)	Interpretive, ethnography/ Tape recorded separate semi-structured open-ended interviews/ Constant comparative analysis	21 adults and children from 8 families where an individual is diagnosed with AIDS/HIV	Long term family goals and normalization strategies	Member checking	Findings linked to other research	Peer review	Member checking; Findings linked to examples from the data
48. Antle et al (2001)	Not addressed/ Interview/Content analysis	105 parents from 86 families where the mother is HIV positive	Demands of parenting in families living with HIV/AIDS	Data linked to coding categories	Description of sample	Not addressed	Findings linked to examples from the data
49. Guthrie & Castelnuovo (2001)	Phenomenology/ Audiotaped open-ended structured interviews/ Inducted content analysis	34 adult females with disability (spinal cord injury, congenital limb deficiency, amputation, acquired brain injury, post-polio syndrome, multiple sclerosis, amyotrophic lateral sclerosis, spina bifida, dwarfism	Disability management themes	Peer debriefing; Transcripts confirmed by interviewees	Findings linked to other research	Coding checks	Findings linked to examples from the data

Appendix A continued

Author/ Date	Approach/ Method/ Analysis	Number in Study	Major Findings	Credibility	Transferability	Dependability	Confirmability
50. Jirapaet (2001)	Phenomenology/ Maternal Behavioral Questionnaire, 2 Audiotaped unstructured in-depth interviews/ Content analysis	39 low-income, Thai, HIV-positive mothers exhibiting successful adaptation	6 factors identified for use of internal and external resources to attain their maternal roles	Bias bracketing	Findings linked to other research	Coding checks	Findings linked to examples from the data
51.Scherman Dahlgred, & Lowhagen (2002)	Phenomenology/ 2 open-ended interviews over 8 years/ Content analysis	30 adults with suspected asthma	14 themes describing the illness experience including identity	Peer debriefing/ Data collected long term	Description of sample; Findings linked to other research	Coding checks for consensus	Findings linked to examples from the data

APPENDIX B: QUESTIONNAIRE (see key on page 143)

INSTRUCTIONS: Please fill in the answers to the questions below.

1. Age: _______________ 2. Sex: _____

3. Race: _______________________________________

(Caucasian, African American, American Indian, Asian, Other)

4. Are you of Hispanic origin?_______

5. Education Level (please check the highest level of education completed):
Less than high school _____
High school/ GED _____
Technical school _____
Some college _____
College degree _____
Graduate degree _____

6. Marital Status (please check the response that describes you):
Single _____
Married/Partnered _____
Separated _____
Divorced _____
Widowed _____

7. Medical Diagnoses (please list all current illnesses and the approximate date diagnosed):

Diagnosis	Year

8. Family Members Living With You Now (please list family members by their relationship to you and their ages – for example: son, 20 years):

Family Member Relationship	Age

INSTRUCTIONS: Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally. **Place an "x" in the space under "True" if you feel it is true or mostly true about you. Place an "x" in the space under "False" if you feel it is false or mostly false about you.**

		True	False
9.	I'm willing to admit it when I make a mistake.	_____	_____
10.	I like to gossip at times.	_____	_____
11.	There have been occasions when I took advantage of someone.	_____	_____
12.	I always try to practice what I preach.	_____	_____
13.	I sometimes try to get even rather than forgive and forget.	_____	_____
14.	I never resent being asked to return a favor.	_____	_____
15.	I have never been irked when people expressed ideas very different from my own.	_____	_____

16. At times I have really insisted on having things my own way. _____ _____

17. There have been occasions when I felt like smashing things. _____ _____

18. I have never deliberately said something that hurt someone’s feelings. _____ _____

INSTRUCTIONS: For this portion of the questionnaire, consider your rheumatoid condition and circle the number that corresponds to how much your illness or its treatment interfere with aspects of your life. Under each statement is a scale which ranges from **Not Very Much (1) to Very Much (7).** Circle the choice that is true FOR YOU.

19. How much does your illness and/or its treatment interfere with your health?

Not Very Much 1 2 3 4 5 6 7 Very Much

20. How much does your illness and/or its treatment interfere with your diet (the things you eat and drink)?

Not Very Much 1 2 3 4 5 6 7 Very Much

21. How much does your illness and/or its treatment interfere with your work?

Not Very Much 1 2 3 4 5 6 7 Very Much

22. How much does your illness and/or its treatment interfere with your active recreation (e.g., sports)?

Not Very Much 1 2 3 4 5 6 7 Very Much

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23. How much does your illness and/or its treatment interfere with your passive recreation (e.g., reading, listening to music)?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

24. How much does your illness and/or its treatment interfere with your financial situation?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

25. How much does your illness and/or its treatment interfere with your relationship with your spouse?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

26. How much does your illness and/or its treatment interfere with your sex life?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

27. How much does your illness and/or its treatment interfere with your family relationships?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

28. How much does your illness and/or its treatment interfere with your other social relationships?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

29. How much does your illness and/or its treatment interfere with your self-expression/self-improvement?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

30. How much does your illness and/or its treatment interfere with your religious expression?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

31. How much does your illness and/or its treatment interfere with your community and civic involvement?

Not Very Much 1 2 3 4 5 6 7 Very Much

---

32. I frequently attend support group activities offered for people with my condition.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

---

33. I treat problems related to my condition as part of everyday life.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

---

34. I am normal except for my condition.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

---

35. I pace myself during the day in order to conserve energy.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

36. I always maintain a normal appearance to others in the way I physically look.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

37. I avoid taking medications in public.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

38. In most ways my life is close to my ideal.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

39. Treatment for my condition is part of staying healthy.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

40. I am better off than most people with my condition.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

41. I have maintained social interactions with others despite my condition.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

42. I live a normal life.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

43. I like to talk about my condition with others.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

44. I seek as much information as I can about the progression of my condition.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

45. The conditions of my life are excellent.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

46. Everybody treats me normally.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

47. There are worse things than being diagnosed with this illness.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

48. I structure my activities to maintain normalcy.

Not at all true for me 1 2 3 4 5 6 7 Very true for me

49. I accept my condition

Not at all true for me 1 2 3 4 5 6 7 Very true for me

50. I engage in activities such as exercise to feel normal.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

51. I choose to skip more trivial activities so that I have the energy to participate in activities that I really value.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

52 . I am satisfied with my life.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

53. Treatment for my condition interferes with my normal life.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

54. I'm like everyone else - everyone has to contend with something in life.

Not at all true 1 2 3 4 5 6 7Very true
for me for me

55. I maintain a normal appearance in the way I behave.

Not at all true 1 2 3 4 5 6 7Very true
for me for me

56. Keeping a routine is important to me.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

57. Treatment is part of my normal life.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

58. Dealing with my condition is part of the daily routine.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

59. I haven’t changed the things I do since being diagnosed with this condition.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

60. I hide the fact that I have this condition from most other people.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

61. I tell others when I have pain.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

62. I try to hide any outward indications of my condition.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

63. I’m able to incorporate the treatment for my condition into my normal life activities.

Not at all true for me	1	2	3	4	5	6	7	Very true for me

64. I freely tell other people about my condition.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

65. I avoid situations with similar others that remind me of my condition.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

66. So far I have gotten the important things I want in life.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

67. I give excuses for any accidents in order to hide my condition.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

68. I behave as if I’m in pain when I have pain.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

69. I avoid using any helpful aids that call attention to my condition.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

70. I avoid situations that may result in feelings of embarrassment.

Not at all true for me	1	2	3	4	5	6	7 Very true for me

71. I only tell those closest to me about my condition.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

---

72. If I could live my life over, I would change almost nothing.

Not at all true 1 2 3 4 5 6 7 Very true
for me for me

<u>INSTRUCTIONS:</u> Below are statements with which you may agree or disagree. Using the scale below the question ranging from (1) strongly disagree to (5) strongly agree, circle the choice that is true for you.

73. It is difficult for me to find effective solutions for problems that occur with managing my medical condition.

Strongly 1 2 3 4 5 Strongly
Disagree Agree

---

74. I find efforts to change things I don't like about my medical condition are ineffective.

Strongly 1 2 3 4 5 Strongly
Disagree Agree

---

75. I handle myself well with respect to my medical condition.

Strongly 1 2 3 4 5 Strongly
Disagree Agree

---

76. I am able to manage things related to my medical condition as well as most other people.

Strongly 1 2 3 4 5 Strongly
Disagree Agree

77. I succeed in the projects I undertake to manage my condition.

Strongly Disagree	1	2	3	4	5	Strongly Agree

78. Typically, my plans for managing my condition don’t work out well.

Strongly Disagree	1	2	3	4	5	Strongly Agree

79, No matter how hard I try, managing my condition doesn’t turn out the way I would like.

Strongly Disagree	1	2	3	4	5	Strongly Agree

80. I’m generally able to accomplish my goals with respect to managing my condition.

Strongly Disagree	1	2	3	4	5	Strongly Agree

81. My condition is controlling my life.

Strongly Disagree	1	2	3	4	5	Strongly Agree

82. I would feel helpless if I couldn’t rely on other people for help with my condition.

Strongly Disagree	1	2	3	4	5	Strongly Agree

83. I am concerned that medicines cannot help me.

Strongly Disagree	1	2	3	4	5	Strongly Agree

84. The side effects of medicines are often worse than the disease.

Strongly Disagree	1	2	3	4	5	Strongly Agree

85. I often do not take my medicines as directed.

Strongly Disagree	1	2	3	4	5	Strongly Agree

86. No matter what I do, or how hard I try, I just can’t seem to get relief from my symptoms.

Strongly Disagree	1	2	3	4	5	Strongly Agree

87. I am not coping effectively with my condition.

Strongly Disagree	1	2	3	4	5	Strongly Agree

88. It seems as though fate and other factors beyond my control affect my condition.

Strongly Disagree	1	2	3	4	5	Strongly Agree

INSTRUCTIONS: For this portion of the questionnaire, circle the number that corresponds to what extent you've felt the feeling or emotion during the **PAST FEW WEEKS**. Under each feeling or emotion is a scale which ranges from Very slightly or not at all (1) to Extremely (5). For the questions below, circle the choice that is true **FOR YOU**.

89. To what extent have you felt interested during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

90. To what extent have you felt distressed during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

91. To what extent have you felt excited during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

92. To what extent have you felt upset during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

93. To what extent have you felt strong during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

94. To what extent have you felt guilty during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

95. To what extent have you felt scared during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

96. To what extent have you felt hostile during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

97. To what extent have you felt enthusiastic during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

98. To what extent have you felt proud during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

99. To what extent have you felt irritable during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

100. To what extent have you felt alert during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

101. To what extent have you felt ashamed during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

102. To what extent have you felt inspired during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

103. To what extent have you felt nervous during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

104. To what extent have you felt determined during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

105. To what extent have you felt attentive during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

106. To what extent have you felt jittery during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

---

107. To what extent have you felt active during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

---

108. To what extent have you felt afraid during the past few weeks?

1	2	3	4	5
Very slightly Or not at all	A little	Moderately	Quite a bit	Extremely

INSTRUCTIONS: On the scales below, mark an X on the lines to depict how much fatigue and pain you experienced in the past week.

109. How much of a problem has unusual fatigue or tiredness been for you OVER THE PAST WEEK? Place a mark (X) on the line below:

Fatigue is Fatigue is a
Not a Problem____ Major
Problem

110. How much pain have you had because of your condition IN THE PAST WEEK? Place a mark (X) on the line below:

No Pain____Pain as Bad
As it Could Be

INSTRUCTIONS: Listed below are words considered to be opposites. Place an "X" on the blank that most closely represents your perception of yourself in relationship to the words.

Myself

111. hard ____:____:____:____:____:____:____ soft

112. good ____:____:____:____:____:____:____ bad

113. dependent ____:____:____:____:____:____:____ independent

114. unfair ____:____:____:____:____:____:____ fair

115. fast ____:____:____:____:____:____:____ slow

116. cold ____:____:____:____:____:____:____ hot

117. large ____:____:____:____:____:____:____ small

118. heavy ____:____:____:____:____:____:____ light

119. dull ____:____:____:____:____:____:____ sharp

120. dirty ____:____:____:____:____:____:____ clean

INSTRUCTIONS: Listed below are words considered to be opposites. Place an "X" on the blank that most closely represents your perception of most people who are sick in relationship to the words.

Most Persons Who Are Sick

121. sharp ____:____:____:____:____:____:____ dull

122. fair ____:____:____:____:____:____:____ unfair

123. light ____:____:____:____:____:____:____ heavy

124. clean ____:____:____:____:____:____:____ dirty

125. slow ____:____:____:____:____:____:____ fast

126. hard ____:____:____:____:____:____:____ soft

127. cold ____:____:____:____:____:____:____ hot

128. small ____:____:____:____:____:____:____ large

129. independent ____:____:____:____:____:____:____ dependent

130. good ____:____:____:____:____:____:____ bad

INSTRUCTIONS: Circle the answers to the questions below.

131. How many close friends would you say you have? That is, people that you feel at ease with, can talk to about private matters, and can call on for help?

None 1 or 2 3-5 6-9 10 or more

132. How many relatives do you have that you feel close to?

None 1 or 2 3-5 6-9 10 or more

133. How many people do you know who you feel understand your condition?

None 1 or 2 3-5 6-9 10 or more

INSTRUCTIONS: For this portion of the questionnaire, circle the number that corresponds to the amount of difficulty you experience in doing these tasks. Under each statement is a scale which ranges from without ANY difficulty (1) to UNABLE to do (4). On the questions below, circle the choice that is true FOR YOU.

134. AT THIS MOMENT, are you able to dress yourself, including tying shoelaces and doing buttons?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

135. AT THIS MOMENT, are you able to get in bed and out of bed?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

136. AT THIS MOMENT, are you able to life a full cup or glass to your mouth?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

137. AT THIS MOMENT, are you able to walk outdoors on flat ground?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

138. AT THIS MOMENT, are you able to wash and dry your entire body?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

139. AT THIS MOMENT, are you able to bend down to pick up clothing from the floor?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

140. AT THIS MOMENT, are you able to turn regular faucets on and off?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

141. AT THIS MOMENT, are you able to get in and out of a car, bus, train or airplane?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

142. AT THIS MOMENT, are you able to walk two miles?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

143. AT THIS MOMENT, are you able to participate in sports and games as you would like?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

144. AT THIS MOMENT, are you able to get a good night’s sleep?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

145. AT THIS MOMENT, are you able to deal with feelings of anxiety or being nervous?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

146. AT THIS MOMENT, are you able to deal with feelings of depression or feeling blue?

1	2	3	4
Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do

<u>INSTRUCTIONS:</u> Listed below are statements that describe how people may choose to deal with chronic illness. Under each statement is a scale which ranges from (1) --"I usually don't do this at all" to (4)-- "I usually do this a lot". For the questions below, circle the answer that indicates how frequently you use the tactic to cope with your chronic condition.

IN DEALING WITH MY MEDICAL CONDITION:

147. I try to grow as a person as a result of the experience.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

148. I turn to work or other substitute activities to take my mind off things.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

149. I concentrate my efforts on doing something about it.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

150. I say to myself “this isn’t real”.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

151. I admit to myself that I can’t deal with it, and quit trying.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

152. I accept that this has happened and that it can’t be changed.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

153. I focus on dealing with this problem, and if necessary let other things slide a little.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

154. I try to come up with a strategy about what to do.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

155. I do what has to be done, one step at a time.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

156. I look for something good in what is happening.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

157. I refuse to believe that it has happened.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

158. I go to movies or watch TV, to think about it less.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

159. I daydream about things other than this.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

160. I just give up trying to reach my goal.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

161. I take additional action to try to get rid of the problem.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

162. I think about how I might best handle the problem.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

163. I get used to the idea that it happened.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

164. I put aside other activities in order to concentrate on this.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

165. I accept the reality of the fact that it happened.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

166. I reduce the amount of effort I’m putting into solving the problem.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

167. I learn something from the experience.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

168. I give up the attempt to get what I want.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

169. I act as though it hasn’t even happened.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

170. I keep myself from getting distracted by other thoughts or activities.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

171. I sleep more than usual.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

172. I try hard to prevent other things from interfering with my efforts at dealing with this.

1	2	3	4
I usually don’t do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

---

173. I pretend that it hasn't really happened.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

174. I make a plan of action.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

175. I take direct action to get around the problem.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

176. I try to see it in a different light, to make it seem more positive.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

177. I learn to live with it.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

178. I think hard about what steps to take.

1	2	3	4
I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot

I WOULD LIKE INFORMATION ABOUT THE RESULTS OF THIS RESEARCH STUDY:

YES NO

THANK YOU FOR YOUR PARTICIPATION!

ADDITIONAL COMMENTS:

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_______________PLEASE MAIL TO:

CYNTHIA O’NEAL, 3601 4TH STREET, STOP 6221, LUBBOCK, TX 79430-6221

Key For Questionnaire

Measure	**Item Numbers in Questionnaire**
Demographic Information	1-8
Social Desirability	9-18
Illness Intrusiveness Rating Scale	19-31
Normalization	32-37; 39-44; 46-51; 53-65; 67-71
Life Satisfaction Scale	38, 45, 62, 66, 72
Perceived Medical Condition Self Management Scale	73-80
RAI	81-88
PANAS	89-108
MDHAQ	109-110, 134-146
Sick Role Acceptance Measure	111-130
Social Ties	131-133
COPE: Positive Reinterpretation	147, 156, 167, 176
COPE: Mental Disengagement	148, 158, 159, 171
COPE: Active Coping	149, 155, 161, 175
COPE: Denial	150, 157, 159, 169
COPE: Behavioral Disengagement	151, 160, 166, 168
COPE: Acceptance	152, 163, 165, 177
COPE: Suppression of Competing Activities	153, 164, 170, 172
COPE: Planning	154, 162, 174, 178

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