ABSTRACT

The link between relationship variables, psychological health, and physical health has been well established in the research literature; however, understanding the interaction between these variables remains unclear. In particular, partner support and relationship adjustment have remained largely separate and the concepts have rarely been examined together (Acitelli, 1996). As a result, little is known about their relationship and collective role in influencing the adjustment of chronically ill populations, specifically systemic lupus erythematosus (Reisine, 1993; Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991).

The objectives for this study were: 1) to identify the levels of psychosocial adjustment to illness and psychological distress among 89 SLE patients, and 2) to assess if partner support and relationship adjustment interact in predicting psychosocial outcomes among SLE patients. Hierarchical regressions were used to predict psychosocial adjustment to illness and psychological distress.

Although the objective of finding an interaction effect between relationship adjustment and partner support was not achieved, findings suggest that the context of the relationship does add to our knowledge in terms of partner support. For SLE patients in both distressed and nondistressed
relationships, it is not how helpful the partner is, but rather how unhelpful they are that relates to psychosocial outcomes. In this regard, research and clinical intervention must influence one another to promote an effective balance between health, support, and relationship adjustment. Future research and clinical implications for marriage and family therapists are discussed.
Dedicated to the greatest source of support - Bradford Lewis, Jr.,
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CHAPTER 1

INTRODUCTION

Statement of the Problem

The leading causes of death in America over the past century have slowly transitioned from infectious and acute to chronic and degenerative diseases. For example, in 1900 the leading causes of death were influenza and pneumonia, whereas today heart disease consistently ranks as the number one cause of death for both men and women (Taylor, 1999). Omran (1971) coined the term “epidemiologic transition” to describe the shift in Americans living longer but with debilitating illnesses such as heart disease, diabetes, and autoimmune diseases. This shift has resulted in few close relationships in adulthood remaining untouched by the effects of health-related problems. The fact that many disabling effects from chronic illness occur later in life suggests limitations from these illnesses are likely to be experienced within a partnered relationship.

Debilitating or chronic illnesses have been shown to have numerous effects on patients as well as their relationships with family and friends. Two themes have emerged in the research on relationships and illness: (1) chronic illnesses impact close relationships and (2) close relationships affect coping with and adaptation to health problems. In a review of how disabling health
problems affect close relationships, Lyons, Sullivan, Ritvo, and Coyne (1995) found that there was an increase in marital and family difficulties, a reduction in the frequency and spontaneity of social contacts, and the termination of activity-based contacts (work, leisure, and community). In addition, there is considerable loneliness and isolation among people living with chronic illnesses and their partners. One reason for this is that care giving demands disrupt lifestyle routines and place substantial demands on family members. For example, one study found that over one-half of families caring for a chronically ill member experienced at least one major adverse impact from the illness, such as financial setbacks, career and educational changes, or relocating to a less expensive living arrangement (Covinsky, et al., 1994).

Relationships, however, have been found to be a source of support in coping with and adjusting to illness by providing emotional and instrumental aid (Cobb, 1976). Family support provides an array of resources to the chronically ill such as protection against psychological distress, monetary resources, and instrumental support. Although there has been considerable literature concerning how individuals cope with chronic illness, increased attention to how families impact patient’s physical and psychological health outcomes has emerged in the past fifteen years (Campbell, 1986). For example, the stress or social strain model has investigated how social relationships can hinder well-being (Coyne & DeLongis, 1986; Rook, 1990). Distressed marriages can lead to illness, exacerbate symptoms, or undermine adjustment to illness (Burman & Margolin, 1992). Indeed, it appears that relationship functioning, not just
relationship status, is associated with psychological and physical health outcomes (Kiecolt-Glaser & Newton, 2001). These results highlight the need to assess variables other than relationship status when conducting research on chronically ill patients. Constructs of particular importance include relationship quality and adjustment, as well as the process of dyadic interactions. Relationships are now seen as contributing to both positive and negative outcomes among patients coping with illness (Coyne & DeLongis, 1986).

Although there is an extensive literature on the association between relationships and health, the focus continues to be primarily on the patient, specifically, how social support affects individual outcomes (e.g., well-being, health, adjustment to stress; see Coyne & Downey, 1991, for a review). This line of inquiry is important yet ignores the interpersonal context in which support occurs (Pasch & Bradbury, 1998), limiting our understanding of the dyadic interactions referred to as supportive or unsupportive. Limitations such as these make it difficult for marriage and family therapists (MFT) working with these couples to develop effective clinical interventions.

Relationship Adjustment and Social Support in Chronic Illness

One relational factor that continues to appear in the adjustment to illness literature is couple’s relationship adjustment. Relationship adjustment refers to partners’ subjective evaluation of their relationship (Burman & Margolin, 1992). Lyons, Sullivan, Ritvo, and Coyne (1995) reviewed the relationships and chronic illness literature from the past two decades and concluded that although relationship adjustment has been a variable of interest it has not been
systematically measured. While conceptual and design issues make inferring from or generalizing the results difficult, restricting our range of research to only patients limits our understanding of the context of relationships.

Difficulties in conceptualization of constructs and design methods have plagued the social support literature as well. For example, the social support literature in general has received criticism by Cobb and Jones (1984) because “concepts are fuzzy, definitions are rare, measurement methods are inconsistent and research designs have been weak” (p. 48). In one review, Cutrona (1996) found two broad definitions of social support supported by most theorists. One definition purports social support is the fulfillment by others of basic ongoing requirements for well-being. Others have noted that social support is the fulfillment of more specific time-limited needs that arise as the result of adverse life events or circumstances. In addition, research designs have varied widely resulting in a literature difficult to interpret because of unclear definitions and multiple measurement methods.

A major measurement limitation has been the use of marital status as an index of social support without assessing the extent to which the partners perceive the marriage as supportive (e.g., Berkman & Syme, 1979). This practice presupposes that marital status and support are the same constructs and assumes that all marriages provide some significant level of support. Moreover, minimizing social support to one’s marital status is an oversimplification of the complex process of support within marriage (Acitelli, 1996).
Systemic Lupus Erythematous

One of the most prevalent autoimmune diseases in the United States is systemic lupus erythematosus (SLE; lupus). Autoimmune disease occurs when the body’s immune system mistakenly labels organs, systems, or substances of its own body as invaders and consequently begins to destroy itself (Ravicz, 2000). Current estimates suggest that 5 percent of the population in the United States will have an autoimmune disease in their lifetime (Isenberg & Morrow, 1995). The Lupus Foundation of America reports that approximately 1.4 to 2 million Americans are affected with at least one of the four forms of lupus (discoid lupus, systemic lupus erythematosus, drug-induced lupus, and neonatal lupus). The focus of this study is on SLE as it is the most prevalent form of lupus accounting for 70% of diagnosed cases (Arthritis Foundation, 1996).

Lupus has an unknown etiology (Failla, Kuper, Nick, & Lee, 1996) and is frequently misdiagnosed with other connective tissue maladies such as, rheumatoid arthritis (Rose-Itkoff, 1987). The unpredictability of symptoms makes the adjustment to illness a continual process and especially challenging to relationships. Lupus consists of flares and remissions. A flare is a period of heightened disease activity, whereas a remission is a period of time when symptoms are not evident. Physical symptoms can range from fatigue, fever, weight loss, skin rash, and arthritis to more severe problems such as cardiac, respiratory and renal failure (DaCosta et al., 1999). The onset of physical
symptoms typically occurs during childbearing years (range 15 – 44 years old) with the mean age of twenty-nine (DaCosta et al, 1999; Wiginton, 1999).

Minority women are disproportionately affected by lupus. In fact, women are nine times more likely than men to develop lupus and prevalence in ethnic minorities is two to three times higher than Caucasians. For example, only one in four hundred Caucasian women are diagnosed compared to one in 250 African-Americans (Lahita & Phillips, 1998).

**Psychosocial Outcomes in SLE**

Substantial research has focused on the medical treatment of SLE, while few studies have examined the impact of non-medical factors influencing the psychosocial outcomes in lupus patients. Specifically, little is known about how relationships might impact adjustment to lupus or influence patient’s psychological distress. It is known that women with SLE tend to be at risk for psychological distress, such as depression and anxiety (Giang, 1991; Joyce, Berkebile, Hastings, Yarboro, & Yocum, 1989). In fact, Liang and colleagues (1984) have suggested that psychosocial difficulties are an integral feature of SLE. Psychological distress (e.g., depression) is consistently one of the top three reasons people seek marriage and family therapy (Doherty & Simmons, 1996) making the need to understand factors influencing distress important.

**Relationship Adjustment & Social Support in SLE**

Researchers have yet to address the interpersonal relationships of persons with lupus to any substantial degree. A search in PsycInfo’s database using ‘lupus’ and ‘marital satisfaction’ as keywords only elicited one
unpublished dissertation (Druley, 1996). This is a real gap in the marriage and family therapy literature considering the overwhelming number of women diagnosed with lupus making the potential of treating a couple in therapy where one partner has lupus highly possible.

Lupus patients have had slightly more research attention in terms of social support. A search in PsycInfo's database using 'lupus' and 'social support' as keywords elicited eight references, half of which were unpublished dissertations. Again, this is substantial considering that social support has been associated with positive physical (e.g., enhanced immune function; Helgeson, 1993) and mental (e.g., lower vulnerability to psychopathology; Cohen & Wills, 1985) health outcomes among other healthy adults. Additionally, the absence of significant others in the lupus research is especially noteworthy given that persons are five times more likely to seek support from friends and family than formal support services (Wills, 1992). As marriage and family therapists, we have the opportunity to assist couples and families in therapy on negotiating support within their relationships.

Significance of the Study

Although there is a growing body of literature on partner support in general, very few studies have examined the association of partner support and relationship adjustment. Acitelli (1996) argues “there is an assumption, largely unexamined that spouses’ assessments of marital satisfaction often involve considerations of social support from their partners” (p. 83). If this assumption were true, then spouses’ perceptions of social support should be related to their
marital satisfaction. Unfortunately, researchers often confound their results by using marital satisfaction as a proxy measure of social support (e.g., Weihs, Enright, Howe, & Simmes, 1999) suggesting that all marriages are supportive. The assumption is that the presence of a spouse, regardless of the quality of the relationship, provides protection against disease (Doherty & Campbell, 1988). This complicates how marriage and family therapists should proceed, and limits effective intervention and treatment of couples. For example, would the research indicate that couples need to improve their relationship adjustment or increase their supportive behaviors?

This study seeks to investigate the associations between relationship adjustment and partner supportive and unsupportive behaviors among women with lupus in terms of psychosocial outcomes. In Chapter Two, the psychosocial adjustment to illness and psychological distress literature will be reviewed, including emphasis on how lupus influences these outcomes. Then, a review of how relationship adjustment affects psychosocial outcomes will be presented. Next, partner support will be defined and discussed in terms of supportive and unsupportive behaviors. This is followed by an argument of why relationship adjustment and partner support should be examined together. Finally, the study’s objectives and hypotheses will be outlined.
CHAPTER 2

RELATIONSHIP ADJUSTMENT, PARTNER SUPPORT, AND PSYCHOSOCIAL OUTCOMES IN SYSTEMIC LUPUS ERYTHEMATOSUS

The link between relationship adjustment, social support, and adjustment has been well established in the research literature; however, understanding the interaction between relationship adjustment and social support remains unclear. This chapter will focus on the literature which suggests that relationship adjustment and partner support impact psychosocial outcomes (i.e., psychological distress, adjustment to illness). The psychosocial adjustment to illness and psychological distress of women with lupus will be discussed first. Then, an overview of how relationship adjustment impacts health will be presented. Next, research specific to partner support will be examined, including the impact of supportive and unsupportive behaviors on psychosocial outcomes. Finally, the objectives of this study will be presented.

Psychosocial Outcomes for Women with Lupus

In general, previous studies have examined psychosocial outcomes in terms of health locus of control, social relationships, depression, anxiety, and adjustment to illness. Studies have demonstrated a bi-directional relationship between psychosocial outcomes and physical health (Cohen, 1988; Rodin & Salovey, 1989). In the past 15 years, extensive research has been conducted
to support this relationship; only recently, however, has attention been given to
the antecedents to psychosocial outcomes. That is, what contributes to better
psychosocial outcomes? Several factors have been identified as predictors of
psychosocial outcomes. Factors associated with illness, such as duration,
severity, and progression, have been examined. In addition, factors related to
social relationships including social support networks, marital status, and
relationship adjustment have been studied. For the purpose of this study
however, two psychosocial outcomes are of particular interest, psychosocial
adjustment to illness and psychological distress.

Psychosocial Adjustment to illness

Psychosocial adjustment to illness, defined as an individual’s ability to
physically and emotionally adapt to illness, encompasses several domains,
including social environment, sexual relationships, and family relationships
(Derogatis & Derogatis, 1990). The social environment reflects the status of the
patient’s current interest and participation in leisure activities and the degree to
which the patient has restricted activities due to illness. Patients might also
experience changes in their sexual relationships including their level of
satisfaction with current sexual functioning or frequency of sexual activity. The
illness can also impact family’s normal interactions (i.e., frequency of contact,
quality of relationships, etc.). For example, contact between the patient and
extended family could decrease due to complications with the illness, or interest
in outside activities with one’s spouse could wane.
The process of achieving psychosocial adjustment for women with lupus is a unique experience due to characteristics of the disease. John Rolland’s psychosocial typology of illness is one way to understand the distinctiveness of lupus. Rolland (1984), a leading medical family therapy researcher, developed this psychosocial typology of illness, which enables health care providers to intervene more effectively by having a better understanding of the psychological and interpersonal needs of patients and families based on a particular illness. According to his model, lupus is described as a gradual-onset, chronic, and relapsing/progressive illness. In comparison to an acute-onset illness (e.g., myocardial infarction), which elicits couple’s crisis management response, gradual-onset disorders require an extended period of adjustment. The episodic nature of flare-ups and remissions make adjustment a continual process alternating between stability and crisis for both the patient with lupus and her family (Rose-Itkoff, 1987; Kinash, 1983).

Lupus, along with other relapsing illnesses, requires flexibility in the family’s organization to permit movement in response to flare-ups and periods of remission (Rolland, 1984). In contrast, diseases with a progressive course may require more predictable and stable role change and adaptation within the family system. Although lupus may not be as biologically severe as other illnesses with a constant course, it can be more psychologically challenging. Awareness of the interplay between the patient’s adjustment and lupus’ psychosocial typology can foster a better understanding of the challenges associated with lupus, and the factors that contribute to adjustment.
To date, no studies have compared disease severity and duration specific to predicting psychosocial outcomes among lupus patients. However, one study investigating a similar autoimmune disease found that psychosocial outcomes were associated with disease severity rather than disease duration (Aronson, 1997). Aronson (1997) conducted a survey investigating quality of life with multiple sclerosis (MS) patients and their caregivers and found that patient’s quality of life was associated with MS symptoms and disease course, not disease duration. Because of the unpredictable nature of symptoms in autoimmune diseases, researchers can capture a more accurate representation of the disease’s effects by investigating current symptoms and severity. One study of the relationship of race, socioeconomic status, disease severity, and psychosocial factors found that disease severity was associated with lower self-efficacy, decreased social support, and decreased income in lupus patients (Karlson et al., 1997). Although research on other illnesses and adjustment provide valuable information, it is of interest to examine lupus specifically because the chronic, progressive nature of lupus may differentially impact individual functioning and require a different response.

**Psychological Distress**

Research studies focusing on depression and anxiety in lupus patients are limited. Psychological distress, defined as a patient’s level of distressing thoughts or feelings, is frequently measured using depression and anxiety as indicators. Rogers (1983) reviewed psychiatric aspects of lupus and suggested
that emotional adjustment (i.e., psychological distress) is often hampered due to
the perception of lupus as mysterious, progressive, unpredictable, and fatal.

Depression is frequently reported to be the most common psychological
complication of lupus and has frequently been associated with psychosocial
dysfunction (Bauman, 1989; Ishikura et al, 2001; Iverson, Sawyer, McCracken,
& Kozora, 2001; Wekking, 1993). However to date, few studies have examined
psychological distress specifically in lupus patients. Ishikura and colleagues
(2001) investigated factors associated with depression, anxiety, and suicidal
ideation in 84 Japanese SLE patients. Depression was evaluated using the
Self-rating Depression Scale (SDS) and anxiety was measured using the State-
Trait Anxiety Inventory (STAI). The Cornell Medical Index Health Questionnaire
was utilized for assessing suicidal ideation. In this sample, two factors were
associated with depression, not being married, and not understanding lupus at
the onset of treatment. Anxiety was correlated with the side effects of steroids
(e.g., weight gain, facial hair) and interpersonal problems with family members.
Significant doses of steroids used daily were correlated with suicidal ideation.

In 1991, Giang reviewed studies from 1970 through 1988 which looked at
depression in SLE patients and found prevalence rates ranging from 7-52
percent. The variation in rates of depression may be a result of different
methods of assessment. For example, researchers employing single items to
assess depressive symptoms found higher estimates (around 70%; Liang et al.,
1984) compared to those using standardized measures or interviews which
found estimates to be around 50% (Ganz et al., 1972).
Factors identified as being associated with rates of depression in SLE include disease activity (e.g., Joyce, Berkebile, Hastings, Yarboro, & Yocum, 1989). For example, when studying disease activity in forty-nine lupus patients, researchers found that as symptoms of SLE increased, levels of depression on the Arthritis Impact Measurement Depression subscale also increased (Joyce, Berkebile, Hastings, Yarboro, & Yocum, 1989). Hall and Stickney (1984) examined the emotional state reported by lupus patients and their families and noted that profound lethargy was associated with episodes of spontaneous tearfulness and intermittent feelings of depression. A limitation specific to this study was the authors’ failure to operationalize “emotional state.”

Alterations in physical appearance such as rashes, hair loss, and disfigurement have also been related to depression in patients with SLE (Joyce et al., 1989; Hall & Stickney, 1984). The role of medication and treatment has also gained attention due to their potential psychological impact. For example, the role of corticosteroids (i.e., prednisone) has been suggested as having a direct impact on depressed mood (Brown & Suppes, 1998), although others have suggested little or no impact on affective symptoms (Zvaifler, 1983). Caution should be exercised when diagnosing depression in patients with SLE because some have suggested that depression experienced by this group may be reactive in nature and possibly a chronic low-grade grief reaction associated with feelings of sadness and frustration over the losses that accrue as a result of their illness (Rogers, 1983).
Although not investigated as thoroughly as depression, anxiety is often another psychological factor impacting patients with lupus (Bauman et al., 1989; Ishikura et al., 2001; Wekking, 1993). SLE patients are said to exist in a chronic state of uncertainty (Shontz, 1956). Uncertainty can occur from ambiguous symptoms, complex treatments, inadequate information about the seriousness of the illness, and unpredictable prognosis and disease course (Mishel, 1988). One review of psychiatric symptoms in SLE patients evaluated 21 studies published between 1969 and 1991 and found prevalence rates of anxiety ranged from 7 to 14 percent (Wekking, 1993). Overall, prevalence of psychiatric symptoms in SLE patients was similar to other chronic illnesses not affecting the brain.

During the period of initial diagnosis, lupus patients have been found to report fears of death, incapacitation, financial ruin, inability to maintain a job, insanity, and an extreme sense of frustration related to looking well while feeling so weak that they were unable to function (Hall & Stickney, 1984). Another study investigating the educational needs of SLE patients in New South Wales found that forty-six percent of patients reported anxiety associated with the disease (Bauman et al., 1989). Furthermore, the majority of this sample described difficulty planning for the future. This may be because patients with lupus often exist in a continual state of anxiety.

Fears regarding disability or increased disease severity have also been reported (Liang et al., 1984; Stein, Walters, Dillon, & Schulzer, 1986). In a study determining the psychosocial impact of SLE and rheumatoid arthritis,
forty-four percent ($n = 75$) of lupus patients reported that their biggest fear was the worsening of the disease or disability (Liang et al., 1984). These results should, however, be interpreted cautiously because of the low response rate (20%) for SLE patients.

Anxiety is not limited to factors associated with the illness and patient. Most patients with SLE report fears regarding their ability to continue caring for their partner or children (Stein, Walters, Dillon, & Schulzer, 1986). Thus, interpersonal relationships play an important role in the psychological distress with illness in women with lupus.

Relationship adjustment

A growing literature suggests that negative aspects of social relationships (i.e., strain) are often independent of positive aspects (i.e., support) and each are important independent predictors of psychological and physical functioning (negative aspects - Rook, 1990; Stansfeld, Bosma, Hemingway, & Marmot, 1998; positive aspects – Cohen & Wills, 1985). For example, in one study 166 couples completed daily diaries of stressors experienced for 6 weeks. The findings suggest that interpersonal stressors were more disruptive than noninterpersonal stressors (Bolger, DeLongis, Kessler, & Schilling, 1989). That is, difficulties experienced within the relationships such as, arguments about chores or childcare were more distressing than stress from work. Yet, in a review investigating the association between social support and well-being in both healthy and ill samples, Cohen
and Wills (1985) found evidence that perceived availability of support from relationships buffered the effects of stressful events.

The context of relationships can be useful in identifying how couple interactions shape adaptation (Coyne & Bolger, 1990). In other words, the quality of relationships may affect well-being (Coyne & DeLongis, 1986; Rook, 1984). For example, findings from a case study analysis examining 11 families' response to the mother's chronic illness indicate that an emotionally satisfying and secure partner relationship can contribute greatly to illness adjustment (Hough, Lewis, & Woods, 1991).

Negative aspects of relationships, or social stressors, have been associated with psychiatric manifestations in SLE patients (Lim, Lee, & Boey, 1991). Women are more likely to experience health-related problems if the marriage is distressed (Kiecolt – Glaser et al., 1987; Ewart et al., 1991; Huston & Ashmore, 1986). In one study of 38 married women and 38 separated/divorced women, immunologic assays and written questionnaires were examined to determine the role of marital quality, as measured by the Dyadic Adjustment Scale, and disruption on immune function (Kiecolt-Glaser, et al., 1987). Results suggested that poor marital quality among married women was associated with greater depression and poor immune function, while women separated for a year or less had significantly poorer immune function than did married women. This is compounded when women are also living with an illness.
Partner Support

The lack of focus on relationship-specific support, especially among married couples, has been suggested as a major limitation in the social support literature (Acitelli, 1996; Julien & Markman, 1991). Especially since studies have begun to demonstrate that relationship-specific support makes a significant contribution in predicting adjustment, over and above the more global perceptions of support (Sarason, Sarason, & Pierce, 1994). In fact, in a review of the role of social relationships in adaptation, literature suggested that support from other sources cannot compensate for a lack of partner support (Coyne & DeLongis, 1986).

For the purposes of this study, relationship-specific support will focus on partner support defined as the interactions deemed supportive or unsupportive by persons in a committed relationship. Although potential sources of social support can include any number of individuals in one’s social network, partner support is a unique and important resource frequently utilized (Beach, Martin, Blum, & Roman, 1993; Cutrona, 1996; Julien & Markman, 1991). Partners are also more likely to be responsive to distress, to be accurate about the nature and degree of one’s difficulties, and to provide help appropriate to patient's needs (Vaux, 1988).

Supportive versus Unsupportive Behaviors

The majority of studies focusing on social support have been in the context of other relationships such as, family and friends. One exception was a cross-sectional study investigating 1,269 married persons that found that in the
context of committed relationships supportive behaviors promote emotional adjustment among those with physical illness (Wethington & Kessler, 1986). In a sample of cancer patients, supportive behaviors enhanced well-being while encouraging health behaviors (Taylor & Dakof, 1988). Another study found rheumatoid arthritis patients who perceived their partner as being supportive used more adaptive coping strategies such as, focusing energy on positive aspects of life or making plans for the future (Manne & Zautra, 1989). In married lupus patients, partner support has been shown to be an important factor in terms of achieving good sexual adjustment (Stein, Dillon, & Schulzer, 1986).

The timing of supportive behaviors has also been shown to be an important factor in adjustment among the general population. For example, Bolger, Zuckerman, and Kessler (1998) examined daily diaries from 32 law students preparing for the bar exam and found that examinees' distress did not rise as the exam drew near as long as their partner provided increasing levels of support. While well-timed supportive behaviors have positive effects in the general population, it may not be as realistic an expectation among lupus patients and their partners because of the unpredictable nature of symptoms. While partners’ intentions are to be supportive, poorly timed support may create additional stress for the recipient (Dunkel-Schetter, & Bennett, 1990).

Furthermore, some researchers have suggested that unsupportive behaviors actually are more harmful than supportive behaviors are helpful.
For example, Ewart, Taylor, Kraemer, and Agras (1991) investigated high blood pressure and marital conflict in a study of 43 patients with hypertension. They reported that "not being nasty matters more than being nice" (p. 155). That is, supportive behaviors did not mediate the effect of unsupportive behaviors. Several others have suggested that negative effects of relationships (i.e., unsupportive interactions) may offset the positive effects of relationships (i.e., supportive interactions) (Coyne & Bolger, 1990; Pagel, Erdly, & Becker, 1987).

The Context of Support within Partnered Relationships

Separately, social support and relationship adjustment have been found to be associated with psychosocial outcomes in chronically ill populations (Hall & Stickney, 1984; Julien & Markman, 1991; Kraaimaat, Dam-Baggen, Bijlsma, 1995). However, the associations among relationship adjustment, partner support, and psychosocial outcomes for SLE patients are unknown. One study found that lupus patients with large support systems appeared better-adjusted (Hall & Stickney, 1984); however, relationship adjustment in this study was never assessed. Another study investigated psychosocial outcomes in rheumatoid arthritic women with and without a spouse and found no significant differences between the two groups (Kraaimaat, Dam-Baggen, Bijlsma, 1995). Once again, relationship adjustment was not assessed in this study. Only one study has assessed relationship adjustment and partner support and found that higher levels of marital distress were associated with poorer psychological functioning (Julien & Markman, 1991). Although this study was a major contribution to the marriage and family therapy literature, little was discovered
about the process of how partner support and relationship adjustment interact when predicting psychological outcomes because models were run separately. Studying partner supportive and unsupportive behaviors in the context of relationships would help inform therapeutic interventions based on levels of relationship distress.

By all accounts, the literature with respect to psychosocial outcomes, relationship adjustment, and partner support in the context of lupus is limited. The fragmentation of literature, while inhibiting, also provides some valuable information on where to begin focusing marriage and family therapist’s research attention.

Purpose of Study

Unfortunately, partner support and relationship adjustment have remained largely separate and the concepts have rarely been examined together (Acitelli, 1996). As a result, little is known about their relationship and collective role in influencing the adjustment of chronically ill populations (Reisine, 1993; Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991). The objectives for this study were: 1) to identify the level of psychosocial adjustment to illness and psychological distress among SLE patients, and 2) to assess if partner support and relationship adjustment interact in predicting psychosocial outcomes among SLE patients.
Objectives & Hypotheses of Study

Objective 1

The first objective of this study was to identify the level of psychosocial adjustment to illness and psychological distress among SLE patients. Two research questions were proposed.

Research Question 1: Are SLE patients worse off in terms of their psychosocial adjustment to illness compared to normed data on renal patients?

Research Question 2: Are SLE patients more psychologically distressed compared to normed data on a reference sample of nonpsychiatric females?

Objective 2

The second objective of this study was to assess if partner support and relationship adjustment interact in predicting psychosocial outcomes among SLE patients. Two hypotheses were proposed.

Hypothesis 1: Patients in non-distressed relationships with unsupportive partners will do better in terms of psychosocial adjustment than those in distressed relationships with supportive partners. In other words, the level of relationship adjustment will moderate the relationship between partner supportive and unsupportive behavior and psychosocial adjustment.

Hypothesis 2: Patients in non-distressed relationships with unsupportive partners will do better in terms of psychological distress than those in distressed relationships with unsupportive partners. In other words, the level of relationship adjustment will moderate the relationship between partner supportive and unsupportive behavior and psychological distress.
Figure 2.1: Influence of relationship adjustment and partner support on psychosocial outcomes

<table>
<thead>
<tr>
<th></th>
<th>Non-Distressed</th>
<th>Distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive Partner Behavior</td>
<td>Best Psychosocial Outcomes</td>
<td>Third Best</td>
</tr>
<tr>
<td>Unsupportive Partner Behavior</td>
<td>Second Best</td>
<td>Worst Psychosocial Outcomes</td>
</tr>
</tbody>
</table>
CHAPTER 3

METHODOLOGY

The purpose of this chapter is to introduce the parent study from which the current sample is derived, including recruitment procedures and participant eligibility. Next, sociodemographic characteristics of the current sample are presented followed by a discussion of the measurement of the major variables of interest. Finally, a plan of analyzing the data to investigate the proposed hypotheses is described.

Overview of Study

Participants for the current study were drawn from a larger investigation of an educational intervention of partner support and patient physical, psychological, and role adjustment in systemic lupus erythematosus (Wells, 1999). The Lupus and Relationships study was conducted by, Sharla Wells, a doctoral student at Northwestern University for the purpose of her dissertation. The American Psychological Association and Northwestern University funded this study and couples were recruited from a convenience sample across the U. S., primarily from the greater Chicago and Los Angeles areas from 1994 until 2000.
Recruitment

Multiple methods of recruitment were utilized for this study including mailings and telephone contacts to members of the Chicago Lupus Database and Chicago area rheumatologists, presentations to lupus support groups in Chicago, advertisements in local and national Lupus Foundation newsletters, and direct patient contact by the primary investigator during rheumatology clinic visits in Los Angeles. Participation was on a volunteer basis and monetary compensation was not offered.

After verbal agreement to participate in the study, women and their partners were given two consent forms (patient and partner), two sets of questionnaires (patient and partner), and a postage-paid return envelope. Couples were asked to complete and return the forms to the principal investigator, Sharla Wells, within two weeks. Both patient and partner questionnaires took approximately 90 minutes to complete.

Initially, 131 couples verbally consented to participate in the parent study, however only 96 couples (73%) completed and returned the first set of questionnaires. The highest response rate was for participants recruited through support group contacts (88%) and the lowest response rate was for participants calling to participate after seeing a flyer or an advertisement in the Lupus Foundation newsletter (57%). Participants recruited through the Chicago Lupus Database and the UCLA Outpatient Rheumatology Clinic had similar response rates (72%; 67%, respectively).
Eligibility

The Lupus and relationships study included couples in which women had been diagnosed with lupus for at least six months and were in a committed, cohabiting relationship for at least six months. Both members of the couple had to be at least 18-years old and fluent in English. In addition, both partners had to consent to participate. Ninety-six couples met inclusion criterion and completed baseline questionnaires. The current study focuses on eighty-nine couples who completed all baseline and sociodemographic measures relevant to this study. Seven couples failed to complete several measures relevant to the study and did not respond to follow-up attempts and were therefore dropped from the sample.

Demographics and Disease Characteristics of Patients

Patients ranged in age from 26 to 75 with the mean age of 42 years (see Table 3.1). The average length of lupus diagnosis was 10 years but ranged from less than a year to over 37 years. Patients were female and the majority were Caucasian (n = 64; 72%) with the remainder being African American (n = 18; 20%), Asian American (n = 3; 3%), and Hispanic (n = 2; 2%). Most women were college graduates (n = 41; 46%) and were employed full-time (n = 35; 38%). Most women (n = 43; 48%) also experienced a mild to moderate flare of symptoms during the previous month, while 7 (8%) women reported a severe disease flare. The most frequent symptoms reported in the past month were fatigue (n = 82; 92%), pain or stiffness in joints (n = 57; 64%), and muscle pain (n = 72; 81%).
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Lupus Patients (n = 89)</th>
<th>Partners (n = 89)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (%)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>42.2 (10.3)</td>
<td></td>
</tr>
<tr>
<td>Length of Relationship (years)</td>
<td>16.9 (10.7)</td>
<td></td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>82 (92.1)</td>
<td></td>
</tr>
<tr>
<td>Cohabiting</td>
<td>3 (3.3)</td>
<td></td>
</tr>
<tr>
<td>Common-Law</td>
<td>3 (3.4)</td>
<td></td>
</tr>
<tr>
<td>Same-sex couple</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>64 (71.9)</td>
<td>66 (74.2)</td>
</tr>
<tr>
<td>African American</td>
<td>18 (19.8)</td>
<td>18 (20.2)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (3.4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (2.2)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.1)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1.1)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school diploma</td>
<td>19 (21.3)</td>
<td>19 (21.3)</td>
</tr>
<tr>
<td>Beyond high school</td>
<td>9 (10.0)</td>
<td>11 (12.4)</td>
</tr>
<tr>
<td>College graduate</td>
<td>41 (46.1)</td>
<td>44 (49.4)</td>
</tr>
<tr>
<td>Graduate/Professional</td>
<td>20 (22.4)</td>
<td>14 (15.7)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td>20 (22.5)</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td>Full-time</td>
<td>35 (39.3)</td>
<td>67 (76.4)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (3.4)</td>
<td>8 (9.0)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>14 (15.7)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Seeking Work</td>
<td>1 (1.1)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>Disabled/Medical Leave</td>
<td>16 (18.0)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>Full-time student</td>
<td>0 (0)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Family Income (Yearly)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ $40,000</td>
<td>21 (23.6)</td>
<td></td>
</tr>
<tr>
<td>≥ $41,000</td>
<td>59 (66.2)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>9 (10.1)</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.1: Demographic & disease characteristics of lupus patients and partners (table continues)
Table 3.1: Continued

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Lupus Patients (n = 89)</th>
<th>Partners (n = 89)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (%)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>16 (18.0)</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>14 (15.7)</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>33 (37.1)</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>12 (13.5)</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>6 (6.7)</td>
<td></td>
</tr>
<tr>
<td>Five</td>
<td>5 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Six</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Ten</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Children in Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>35 (39.3)</td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>18 (20.2)</td>
<td></td>
</tr>
<tr>
<td>Two</td>
<td>30 (33.7)</td>
<td></td>
</tr>
<tr>
<td>Three</td>
<td>4 (4.5)</td>
<td></td>
</tr>
<tr>
<td>Four</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Duration of illness (years)</td>
<td></td>
<td>10.3 (7.5)</td>
</tr>
<tr>
<td>Past month’s flare activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No flare</td>
<td>33 (37.1)</td>
<td></td>
</tr>
<tr>
<td>Mild – moderate flare</td>
<td>43 (48.3)</td>
<td></td>
</tr>
<tr>
<td>Severe flare</td>
<td>7 (7.9)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>6 (6.7)</td>
<td></td>
</tr>
<tr>
<td>Disease activity rating</td>
<td>89 (100)</td>
<td>3.7 (2.8)</td>
</tr>
<tr>
<td>Medications used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-inflammatory</td>
<td>36 (40.4)</td>
<td></td>
</tr>
<tr>
<td>Non-steroidal anti-inflammatory drugs</td>
<td>35 (39.3)</td>
<td></td>
</tr>
<tr>
<td>Antimalarials</td>
<td>37 (41.6)</td>
<td></td>
</tr>
<tr>
<td>Immunosuppressive drugs</td>
<td>50 (56.2)</td>
<td></td>
</tr>
</tbody>
</table>
Eighty-two of the couples were married (92%), 3 (3%) were living together, 3 (3%) were common law (living together 7 or more years), and 1 (1%) couple identified themselves as being in a same-sex relationship. These couples had been involved in their current relationships for an average of 16.9 years (R = 2.0 to 49 years). The average number of children for these couples was 2.1 (R = 0 to 10) with an average of 1.1 children living in the home (R = 0 to 4). Most patients reported their family income was over $40,000, suggesting this was a relatively wealthy sample (n = 59: 66%).

Demographics of Partners

Demographic characteristics of partners have been included in order to help describe the lives of the lupus patients. Partners ranged in age from 23 to 76 years with an average of 44 years (see Table 3.1). Eighty-eight (99%) of the partners were male, with only one female partner. Partners were also primarily Caucasian (n = 67; 75%) with African Americans being the largest minority (n = 18; 20%) followed by Hispanics (n = 3; 3%). One partner (1%) was Lebanese. The majority of partners were college educated (n = 44; 49%) and were employed full-time (n = 67; 74%)

Measures

Predictors

Relationship Adjustment. For this study, relationship adjustment was measured using the Revised Dyadic Adjustment Scale (RDAS; Spanier, 1976). The RDAS was designed to improve the psychometric properties of the original 32-item Dyadic Adjustment Scale (DAS) (Busby, Christensen, Crane, & Larson,
The measure consists of 14 items that provide a total score and three subscale scores including dyadic consensus, dyadic satisfaction, and dyadic cohesion (see Table 3.2). Each item is rated on a 6-point scale ranging from 0 = “never” to 5 = “more often”. Examples of items included are “How often do you and your partner quarrel?” or “Do you and your mate engage in outside interests together?” Scores on the RDAS range from 0 to 69 with lower scores indicating poorer adjustment. A cutoff score of 48 discriminates between distressed and non-distressed couples (Crane, Middleton, & Bean, 2000). For this study, the RDAS total score was used.

The RDAS has demonstrated good internal consistency with Cronbach’s alpha coefficients ranging from .80 to .85 on the three subscales and .90 on the total score (Busby et al., 1995). Busby and colleagues (1995) also demonstrated evidence of construct validity by correlating it with the Locke-Wallace Marital Adjustment Test (MAT; \( r = .68, p < .01 \)) and the DAS (\( r = .97, p < .01 \)). Crane et al. (2000) also found high correlations between the RDAS, DAS, MAT, and Kansas Marital Adjustment Scale suggesting good construct validity. Alpha reliability (Cronbach’s alpha) for patients in this sample on the RDAS total was good (\( \alpha = .87 \)).

**Supportive and Unsupportive Behavior.** Partner support was measured using the Partner Response to Illness Measure (PRIM; Wells & Carroll, 2002). The PRIQ is a 46-item behavioral measure developed to assess primary intimate partner support in the context of medical illness (see Appendix A). The PRIQ includes a 23-item Supportive Behaviors scale and a 23-item
Unsupportive Behaviors scale based on exploratory and confirmatory factor analyses. Behaviors are rated on a 5-point scale according to the frequency of each behavior in the past month where 1 = “never” and 5 = “always or almost always.” Example of items asked on the Supportive Behaviors scale are “Spent more time with her,” and “Told her that she would get better.” Items on the Unsupportive Behaviors scale include, “Avoided talking about the illness” and “Attributed problems to the illness.” Higher scores indicate a greater frequency of supportive and unsupportive partner responses. Alpha reliabilities (Cronbach’s alpha) for patients in this sample are good for both Supportive Behaviors ($\alpha = .94$) and for Unsupportive Behaviors ($\alpha = .88$) (see Table 3.2). The Supportive and Unsupportive scales are correlated with other measures of received support in the expected directions (UCLA-Social Support Inventory; Dunkel-Schetter, 1986).

Outcomes

Psychosocial Adjustment. The Psychosocial Adjustment to Illness Scale was used to measure the patient’s psychosocial adjustment to lupus (PAIS-SR; Derogatis & Lopez, 1983). The PAIS-SR is a 46-item multidimensional instrument designed to assess the psychological and social adjustment of medical patients to an illness during the past 30 days. It measures psychosocial adjustment to illness across 7 principal domains: Health Care Orientation, Vocational Environment, Domestic Environment, Social Environment, Extended Family Relationships, Sexual Relationships, and Psychological Distress.
Table 3.2: Number of items, ranges, and alpha coefficients for measures

<table>
<thead>
<tr>
<th>Variable Measure</th>
<th># of Items</th>
<th>Possible Range</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial Adjustment</td>
<td>46</td>
<td>21 to 81</td>
<td>.92</td>
</tr>
<tr>
<td>Psychosocial Adjustment to Illness Scale (Derogatis &amp; Derogatis, 1983)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>90</td>
<td>30 to 81</td>
<td>.66</td>
</tr>
<tr>
<td>Symptom Checklist – 90 – Revised (Derogatis, 1994)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship Adjustment</td>
<td>14</td>
<td>0 to 69</td>
<td>.87</td>
</tr>
<tr>
<td>Dyadic Adjustment Scale – Revised (Spanier, 1976; Busby et al, 1995)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive Behavior</td>
<td>23</td>
<td>23 to 115</td>
<td>.94</td>
</tr>
<tr>
<td>Partner Response to Illness Questionnaire (Wells &amp; Carroll, 2002)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsupportive Behavior</td>
<td>23</td>
<td>23 to 115</td>
<td>.88</td>
</tr>
<tr>
<td>Partner Response to Illness Questionnaire (Wells &amp; Carroll, 2002)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease Activity</td>
<td>21</td>
<td>0 to 63</td>
<td>.86</td>
</tr>
<tr>
<td>Systemic Lupus Activity Questionnaire (Partridge, 1995)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Each item is composed of four statements ranging from 0 = “not a problem” to 3 = “severe difficulty” (see Appendix C). An example of Domestic Environment is, “Has your illness resulted in a decrease in communication between you and members of your family?” An example of Social Environment is, “Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?” The Sexual Relationships domain asks, “Has there been any change in the pleasure or satisfaction you normally experience from sex?” The total score ranges from 0 to 138, which is converted to a t-score with a mean of 50 and standard deviation of 10. Lower scores indicate better adjustment and
higher scores indicate poorer adjustment. For this study, the PAIS total score will be used. Alpha reliability (Cronbach’s alpha) for patients in this sample on the PAIS total score was good (α = .92) (see Table 3.2).

**Psychological Distress.** For this study, psychological distress was measured using the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994). The SCL-90-R includes ninety psychological symptoms rated according to the patient’s experience during the past seven days. Each behavioral symptom is rated on a 5-point scale of distress ranging from 0 = “not at all” to 4 = “extremely”. Examples of items include, “Crying easily,” “Suddenly scared for no reason,” and “Feelings being easily hurt.”

The index derived from the SCL-90-R that is considered the best single indicator of psychological distress is the Global Severity Index (GSI; Derogatis, 1994). The GSI measures overall psychological distress and combines information regarding the level of distress and number of symptoms from nine dimensions (e.g., depression, interpersonal sensitivity, anxiety, hostility, psychoticism). Raw scores on the GSI were converted to area t-scores with a mean of 50 and a standard deviation of 10 based on non-psychiatric patient female norms. Higher scores indicate greater psychological distress with scores above 63 on the GSI considered to be a “positive risk” for psychiatric disorder. The SCL-90-R has demonstrated strong internal consistency, test-retest reliability, and adequate convergent-discriminant validity (Derogatis, Rickels, & Rock, 1976; Koeter, 1992). Alpha reliability (Cronbach’s alpha) for this sample was somewhat low but adequate (α = .66) (see Table 3.2).
Control Variables

Several demographic variables were used as control variables in the current study. Specifically, patient’s age, race, level of disease activity, family income, and length of relationship were covariates. This information, with the exception of disease activity, was taken from the Background Information Sheet (see Appendix B) drafted for the Lupus and Relationships study.

**Patient’s age** was calculated in years since birth.

**Patient’s race** was determined by asking patients to choose between the following response items including African-American, American-Indian, Asian, Caucasian, Hispanic, or other. A space was provided next to the “other” response for patients to specify. For analyses, a dummy variable was created for race, 0 = Other (n = 25) and 1 = Caucasian (n = 64).

**Family income** was assessed by having patients choose from 7 categories from less than $10,000 to over $100,000 in $20,000 increments. For analyses, a dummy variable was created for family income, 0 = $40,000 or less (n = 21) and 1 = $40,000 or more (n = 59). The split was based on the national average income of $36,214 (U.S. Census Bureau, 2002). Nine values were missing and were not included in the analyses.

**Length of Relationship** was calculated by the number of years the patient has been in a relationship with their current partner.

**Disease Activity.** In order to measure patient’s disease activity, the Systemic Lupus Activity Questionnaire was used (SLAQ; Partidge, 1995). The
SLAQ is a 26-item self-report measure of systemic lupus disease activity developed at Brigham and Women’s Hospital in Boston. The disease activity Total Score is the sum of the severity ratings for 24 specific symptoms including rashes, chest pain with deep breath, butterfly rash, fatigue, etc. (see Appendix C). These symptoms were rated from 0 = “no problem” to 3 = “severe.” Higher scores indicate greater disease activity. Alpha reliability (Cronbach’s alpha) for this sample was good ($\alpha = .86$) (see Table 3.2). This measure has demonstrated high correlations with a reliable, valid physician-rated measure of disease activity ($r = .67$ to $.72$ with SLAQ; Liang, Socher, Larson, & Schur, 1989) in at least two other patient samples (Karlson, 1999).

All other variables (number of children, number of children living in the home, patient and partner’s level of education and employment status, and partner’s age, gender, and race) were used to provide descriptive information regarding patient and partner’s social characteristics.

Statistical Plan for Analyses

All data were entered, scored, and analyzed using SPSS 11.0 (SPSS Inc., 2002), with the exception of the disease activity measure which was scored using SAS due to copyright restrictions on the scoring program. Data (100%) has also been verified following entry comparing each patient’s questionnaire to the dataset. For each construct scoring procedures were based on the manual’s instructions. Means and standard deviations were used to provide descriptive information and alpha reliabilities were calculated to determine internal consistency of each measure (see Table 3.2).
Chi-square and t-tests were used to examine the differences on demographic and outcome variables between the two groups, non-distressed and distressed relationships. In order to maximize power, zero-order correlations were used to select demographic variables for inclusion in subsequent analyses. A probability value of less than .05 was used to indicate statistical significance in all analyses.

In order to test the proposed hypotheses, the following methods were utilized:

**Research Question 1:** Are SLE patients worse off in terms of their psychosocial adjustment to illness compared to renal patients?

The t-value was calculated comparing the means of renal patients and SLE patients. Scores for renal patients were included in the PAIS manual.

**Research Question 2:** Are SLE patients more psychologically distressed compared to normed data on a reference sample of nonpsychiatric females?

The t-value was calculated comparing the means of nonpsychiatric females and SLE patients. Scores for nonpsychiatric females were included in the SCL-90-R manual.

**Hypothesis 1:** Patients in non-distressed relationships with unsupportive partners will do better in terms of psychosocial adjustment than those in distressed relationships with supportive partners.

Patient race, income, and disease activity, relationship adjustment, and partner supportive and unsupportive behaviors were entered into a hierarchical regression predicting psychosocial adjustment. A dummy variable was created
for relationship adjustment based on the RDAS cutoff score (48) for delineating distressed from non-distressed couples, 0 = distressed (n = 30) and 1 = non-distressed (n = 59). This was then multiplied by unsupportive partner behavior to create an interaction term.

**Hypothesis 2:** Patients in non-distressed relationships with unsupportive partners will do better in terms of psychological distress than those in distressed relationships with supportive partners.

Patient race, income, and disease activity, relationship adjustment, and partner supportive and unsupportive behaviors were entered into a hierarchical regression predicting psychological distress. A dummy variable was created for relationship adjustment based on the RDAS cutoff score (48) for delineating distressed from non-distressed couples, 0 = distressed (n = 30) and 1 = non-distressed (n = 59). This was then multiplied by unsupportive partner behavior to create an interaction term.
CHAPTER 4

RESULTS

This chapter will outline the steps utilized in analyzing the data to test the hypotheses for each of the research objectives. Descriptive statistics, correlational analyses, and hierarchical regression analyses were used to analyze the data.

Psychosocial Outcomes

The first objective of this study was to identify the psychosocial adjustment to illness and psychological distress among SLE patients. For psychosocial adjustment, the t-value was calculated comparing the means of renal patients and SLE patients. For psychological distress, the t-value was calculated comparing the means of nonpatient females and SLE patients. T-scores were used in comparisons on both the PAIS and SCL-90-R. Comparisons were also made between lupus patient’s and comparison groups on all subscales for the PAIS and SCL-90-R. The means, standard deviations, and ranges for the two outcomes are shown in Table 4.1.

Psychosocial Adjustment

Patient’s average psychosocial adjustment score (PAIS Total Score) was 51.5 (SD = 9.9, R = 26 – 80), and was not significantly different compared to
<table>
<thead>
<tr>
<th>Variable Measure</th>
<th>Overall Range for this Sample</th>
<th>Overall Sample M (SD)</th>
<th>Non-distressed Relationships M (SD)</th>
<th>Distressed Relationships M (SD)</th>
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</thead>
<tbody>
<tr>
<td>Psychosocial Adjustment</td>
<td>26 to 80</td>
<td>51 (10.4)</td>
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<tr>
<td>Psychological Distress</td>
<td>34 to 81</td>
<td>58 (9.4)</td>
<td>56 (8.8)</td>
<td>62 (9.1)</td>
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<td>Symptom Checklist – 90 – Revised (Derogatis, 1994)</td>
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<td>Relationship Adjustment</td>
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<td>54 (4.0)</td>
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<td>Dyadic Adjustment Scale – Revised (Spanier, 1976; Busby et al, 1995)</td>
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<tr>
<td>Supportive Behavior</td>
<td>41 to 114</td>
<td>79 (17.4)</td>
<td>85 (15.7)</td>
<td>68 (14.9)</td>
</tr>
<tr>
<td>Partner Response to Illness Questionnaire (Wells &amp; Carroll, 2002)</td>
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<tr>
<td>Unsupportive Behavior</td>
<td>23 to 75</td>
<td>42 (12.0)</td>
<td>37 (9.7)</td>
<td>50 (11.6)</td>
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<td>Partner Response to Illness Questionnaire (Wells &amp; Carroll, 2002)</td>
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<tr>
<td>Disease Activity</td>
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<td>19 (11.6)</td>
<td>15 (9.9)</td>
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<tr>
<td>Systemic Lupus Activity Questionnaire (Partridge, 1995)</td>
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Table 4.1: Means, standard deviations, and ranges for measures
renal dialysis sample \((t = 1.18, p = .24)\). Lupus patients scored higher on all but 3 Domains, including domestic environment, sexual relationships, and extended family. Their highest scores were on the vocational environment \((M = 54.7, \text{SD} = 6.4)\), psychological distress \((M = 51.5, \text{SD} = 8.5)\), social environment \((M = 50.6, \text{SD} = 9.1)\), and healthcare orientation \((M = 50.0, \text{SD} = 9.1)\) subscales.

Twenty percent of the patients \((n = 16)\) in this sample demonstrated clinically significant psychosocial maladjustment given the cutoff score of 62 on this measure \((\text{Derogatis & Derogatis, 1990})\).

**Psychological Distress**

Patient’s average psychological distress score (SCL-90-R Global Severity Index) was 58.1 \((\text{SD} = 9.1, R = 34 – 81)\) which was significantly higher than the reference sample of nonpatient females \((t = 8.02, p<.01)\). Lupus patients scored higher on all subscales, except paranoid ideation. Their highest scores were on the somatization \((M = 60.6, \text{SD} = 10.8)\), obsessive-compulsive \((M = 58.3, \text{SD} = 10.0)\), depression \((M = 57.8, \text{SD} = 8.6)\), and psychoticism \((M = 55.4, \text{SD} = 8.7)\) subscales. Twenty-seven percent of lupus patients in this sample could be said to meet the criteria for psychological “caseness” using a cutoff score of 63 on this measure \((\text{Derogatis, 1994})\).
<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
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<th>4</th>
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<th>11</th>
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<td>.16</td>
<td>.19</td>
<td>-.25</td>
<td>.02</td>
<td>.05</td>
<td>.30*</td>
<td>.25</td>
<td>.52**</td>
<td>.58**</td>
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<td>-.19</td>
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<td>-.18</td>
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<td>.10</td>
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<td>-.03</td>
<td>-.13</td>
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<td>4. Patient Age</td>
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<td>.16</td>
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<td>-.07</td>
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<td>.12</td>
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<td>5. Patient Education</td>
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<td>-.03</td>
<td>-.14</td>
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<td>.01</td>
<td>-.17</td>
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<td>6. Patient Race</td>
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<td>-.20</td>
<td>-.26*</td>
<td>.15</td>
<td>.01</td>
<td>-.16</td>
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<td>7. Relationship Adjustment</td>
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<td>.48**</td>
<td>-.34**</td>
<td>-.10</td>
<td>-.04</td>
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</tr>
<tr>
<td>8. Partner Supportive Behavior</td>
<td>1.0</td>
<td>-.26*</td>
<td>.19</td>
<td>.24</td>
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<td>9. Partner Unsupportive Behavior</td>
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<td>.20</td>
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<td>10. Psychosocial Adjustment</td>
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<td>11. Psychological Distress</td>
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</table>

*p<.05, **p<.01

Table 4.2: Correlations among predictors and outcomes for non-distressed relationships
<table>
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<tr>
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<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Disease Activity</td>
<td>1.0</td>
<td>-0.09</td>
<td>-0.18</td>
<td>0.02</td>
<td>-0.17</td>
<td>-0.20</td>
<td>-0.17</td>
<td>-0.19</td>
<td>0.50**</td>
<td>0.75**</td>
<td>0.76</td>
</tr>
<tr>
<td>2. Family income</td>
<td>1.0</td>
<td>0.08</td>
<td>-0.08</td>
<td>0.45*</td>
<td>0.03</td>
<td>0.34</td>
<td>-0.13</td>
<td>0.04</td>
<td>-0.36</td>
<td>-0.38*</td>
<td></td>
</tr>
<tr>
<td>3. Length of Relation</td>
<td>1.0</td>
<td>0.67**</td>
<td>0.16</td>
<td>-0.09</td>
<td>-0.12</td>
<td>-0.27</td>
<td>-0.03</td>
<td>-0.29</td>
<td>-0.20</td>
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<tr>
<td>4. Patient Age</td>
<td>1.0</td>
<td>0.05</td>
<td>-0.33</td>
<td>-0.36</td>
<td>-0.32</td>
<td>-0.01</td>
<td>-0.11</td>
<td>-0.05</td>
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<tr>
<td>5. Patient Education</td>
<td>1.0</td>
<td>-0.09</td>
<td>0.24</td>
<td>-0.00</td>
<td>0.13</td>
<td>-0.17</td>
<td>-0.22</td>
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<tr>
<td>6. Patient Race</td>
<td>1.0</td>
<td>0.22</td>
<td>0.27</td>
<td>-0.16</td>
<td>0.02</td>
<td>-0.14</td>
<td></td>
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<tr>
<td>7. Relationship</td>
<td>1.0</td>
<td>0.41*</td>
<td>-0.27</td>
<td>-0.23</td>
<td>-0.31</td>
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<td>8. Partner Supportive</td>
<td>1.0</td>
<td>-0.34</td>
<td>-0.12</td>
<td>-0.12</td>
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<tr>
<td>9. Partner Unsupporti</td>
<td>1.0</td>
<td>0.49**</td>
<td>0.55**</td>
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<td>10. Psychosocial</td>
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<tr>
<td>11. Psychological</td>
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</table>

*p<.05, **p<.01

Table 4.3: Correlations among predictors and outcomes for distressed relationships
Interaction of Relationship Adjustment and Partner Support

The second objective was to determine if partner support and relationship adjustment interact in predicting psychosocial outcomes among SLE patients. First, the sample was split into two groups based on their level of relationship adjustment using the RDAS cutoff score. Then, correlations were run between demographic variables, predictors, and outcome variables (see Tables 4.2 and 4.3). For the non-distressed couples, disease activity was significantly correlated with family income (-.33, p<.05), partner supportive behavior (.30, p<.05), psychosocial adjustment (.52, p<.01), and psychological distress (.58, p<.01). Family income and patient’s race was significantly correlated with partner supportive behavior (-.34, -.26, p<.05, respectively). As expected, partner supportive and unsupportive behaviors were negatively correlated (-.26, p<.05). In addition, partner unsupportive behaviors were correlated with psychosocial adjustment (.32, p<.05) but not with psychological distress. Psychosocial adjustment and psychological distress were correlated, as expected (.56, p<.01). Patient’s age and education, and length of relationship were not correlated with either outcome variable.

For the distressed couples, disease activity was significantly correlated with partner unsupportive behavior (.50, p<.01) and psychosocial adjustment (.75, p<.05). Family income was correlated with patient’s education (.45, p<.05) and psychological distress (-.38, p<.05). Partner unsupportive behaviors were correlated with both psychosocial adjustment (.49, p<.01) and psychological distress (.55, p<.01). However, partner supportive behaviors were not
correlated to either. Again, psychosocial adjustment and psychological distress were correlated as expected (.76, p<.01). Patient’s age, education, and race, and length of relationship were not correlated with either outcome variable.

Next, t-values and a chi-square test were performed to compare non-distressed and distressed couples on predictors and outcome variables (see Table 4.4). Differences were found between the non-distressed relationships and distressed relationships on partner supportive (t = -5.0, p<.01) and unsupportive behaviors (t = 5.5, p<.01), psychological distress (t = 3.3, p<.01), and psychosocial adjustment (t = 4.9, p<.01), with relationships found in the expected directions. Disease severity was the only predictor not significantly different.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Non-distressed Relationships</th>
<th>Distressed Relationships</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Activity (SLAQ)</td>
<td>X 15.5</td>
<td>X 19.7</td>
<td>1.8</td>
</tr>
<tr>
<td>Relationship Adjustment (RDAS)</td>
<td>54.3</td>
<td>42.1</td>
<td>-9.0*</td>
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<tr>
<td>Supportive Behaviors (PRIM)</td>
<td>85.1</td>
<td>67.9</td>
<td>-5.0*</td>
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<tr>
<td>Unsupportive Behaviors (PRIQ)</td>
<td>37.4</td>
<td>50.2</td>
<td>5.5*</td>
</tr>
<tr>
<td>Psychological Distress (SCL-90-R)</td>
<td>55.8</td>
<td>62.4</td>
<td>3.3*</td>
</tr>
<tr>
<td>Psychosocial Adjustment (PAIS)</td>
<td>341.7</td>
<td>380.4</td>
<td>4.9*</td>
</tr>
</tbody>
</table>

*p<.01

Table 4.4: T-Tests comparing distressed and non-distressed relationships
A Chi-square test was performed to compare the non-distressed and distressed relationship groups in terms of race and income. Patient race was significantly different for the groups in this sample [$\chi^2(1, n = 89) = 7.73, p < .05$] with a greater number of minority participants in the distressed group. There were no differences found for family income between the two groups.

Finally, hierarchical regressions were performed to test the interaction between partner unsupportive behavior and relationship adjustment. In order to maximize power, zero-order correlations were used to select demographic variables for inclusion in these analyses only if they were significantly correlated with dependent variables. Psychosocial adjustment, as measured by the PAIS-SR total score, and psychological distress, as measured by the SCL-90-R Global Severity Index, were used as dependent variables in these analyses. In addition, disease activity, as measured by the SLAQ total score, was used as a covariate. A dummy variable was created for relationship adjustment based on the RDAS cutoff score (48) for delineating distressed from non-distressed couples, 0 = distressed (n = 30) and 1 = non-distressed (n = 59). Patient race and income were entered into step one, followed by disease activity in step two, relationship adjustment in step three, partner supportive behaviors in step four, partner unsupportive behaviors in step five, and the interaction term, partner unsupportive behaviors X relationship adjustment, in step six.

**Interaction predicting Psychosocial adjustment**

The final model predicting psychosocial adjustment explained 46% (adj $R^2$) of the variance [$F (7, 72) = 10.49, p<.001$]. Each step of the model was
significant with the exception of step four (partner supportive behavior) and step six (the interaction term) (see Table 4.5). However, in the final model disease activity was the only significant predictor accounting for 42% of the variance in psychosocial adjustment. The interaction term, partner unsupportive behaviors X relationship adjustment, did not contribute significantly in predicting psychosocial adjustment in this sample. The interaction term suppressed the effect of partner unsupportive behavior’s effect in predicting psychosocial adjustment. For example, in step five partner unsupportive behaviors was significant ($\beta = .25, p < .05$), but became nonsignificant in step six ($\beta = .29, p = .07$). Furthermore, the effects of relationship adjustment in predicting psychosocial adjustment may be suppressed by partner unsupportive behavior as evidenced by the change in $\beta$ from steps three to five.

**Interaction predicting Psychological distress**

The final model predicting psychological distress explained 46% (adj $R^2$) of the variance [$F (7, 72) = 10.71, p < .001$]. Step one (patient race and income), step two (disease activity), and step five (partner unsupportive behavior) were the only significant predictors of psychological distress (see Table 4.6). In the final model disease activity was the only significant predictor accounting for 44% of the variance in psychological distress. The interaction term, partner unsupportive behaviors X relationship adjustment, did not contribute significantly to the prediction of psychological distress in this sample. Again, it appears that the interaction term suppressed the effect of partner unsupportive behaviors in predicting psychological distress. For example, in step five partner
unsupportive behaviors was significant ($\beta = .31, p<.05$), but became
nonsignificant in step six ($\beta = .27, p = .07$). Relationship adjustment was not a
significant predictor in any step.
<table>
<thead>
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<th>Variable</th>
<th>β</th>
<th>t-value</th>
<th>R² Change</th>
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<tbody>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Family Income&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>-1.4</td>
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</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease Activity</td>
<td>.42***</td>
<td>4.5</td>
<td></td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Relationship Adjustment&lt;sup&gt;c&lt;/sup&gt;</td>
<td>-.16</td>
<td>-.41</td>
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<td><strong>Step 4</strong></td>
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<td></td>
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<tr>
<td>Supportive Behaviors</td>
<td>.07</td>
<td>.69</td>
<td></td>
</tr>
<tr>
<td><strong>Step 5</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>.29</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Unsupportive Behaviors X</td>
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<td>-.33</td>
<td></td>
</tr>
<tr>
<td>Relationship Adjustment</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Full Model Statistics**

- Multiple R: .711
- Adjusted Multiple R<sup>2</sup>: .457
- F(df1, df2): 10.494 (7, 72)**

**Note:** β = standardized beta coefficient for full model.

<sup>a</sup>Coded as 1 = Caucasian, 0 = Other.
<sup>b</sup>Coded as 1 = ≥ $40,000, 0 = < $40,000.
<sup>c</sup>Coded as 1 = RDAS ≥ 49, RDAS ≤ 48,
*<p>.05, **<p>.01, ***<p>.001

Table 4.5: Hierarchical Regression table predicting Psychosocial Adjustment
<table>
<thead>
<tr>
<th>Variable</th>
<th>( \beta )</th>
<th>t-value</th>
<th>( R^2 ) Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Race(^a)</td>
<td>-.13</td>
<td>-1.4</td>
<td>.18**</td>
</tr>
<tr>
<td>Family Income(^b)</td>
<td>-.16</td>
<td>-1.8</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td>.25***</td>
</tr>
<tr>
<td>Disease Activity</td>
<td>.44***</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td>.08</td>
</tr>
<tr>
<td>Relationship Adjustment(^c)</td>
<td>-.16</td>
<td>-.42</td>
<td></td>
</tr>
<tr>
<td><strong>Step 4</strong></td>
<td></td>
<td></td>
<td>.00</td>
</tr>
<tr>
<td>Supportive Behaviors</td>
<td>.07</td>
<td>.68</td>
<td></td>
</tr>
<tr>
<td><strong>Step 5</strong></td>
<td></td>
<td></td>
<td>.06**</td>
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<tr>
<td>Unsupportive Behaviors</td>
<td>.28</td>
<td>1.8</td>
<td></td>
</tr>
<tr>
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<td></td>
<td>.00</td>
</tr>
<tr>
<td>Unsupportive Behaviors X</td>
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<td>.32</td>
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</table>

**Full Model Statistics**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple R</td>
<td>.714</td>
</tr>
<tr>
<td>Adjusted Multiple ( R^2 )</td>
<td>.462</td>
</tr>
<tr>
<td>( F(df_1, df_2) )</td>
<td>10.710 (7, 72)**</td>
</tr>
</tbody>
</table>

**Note:** \( \beta \) = standardized beta coefficient for full model.

\(^a\)Coded as 1 = Caucasian, 0 = Other.

\(^b\)Coded as 1 = $\geq$ 40,000, 0 = < $40,000.

\(^c\)Coded as 1 = RDAS $\geq$ 49, RDAS $\leq$ 48,

*\( p<.05 \), **\( p<.01 \), ***\( p<.001 \)

Table 4.6: Hierarchical Regression table predicting Psychological Distress
Post-Hoc Analyses

Jaccard, Turrisi, and Wan (1990) suggest there are times when interaction effects fail to manifest, even when they are predicted on the basis of common sense or a strong theory. They suggest that several reasons exist as to why interaction effects may go undetected such as, problems related to multicollinearity, measurement error, inappropriate metrics, small sample sizes, and model misspecification. Because this study was limited to an existing dataset, most of these issues could not be addressed. However, in order to better understand the association between relationship adjustment and partner support in terms of their relationship to psychosocial adjustment and psychological distress, post hoc analyses were conducted. These analyses included performing hierarchical regressions investigating the relative contribution of partner supportive and unsupportive behavior to the psychosocial adjustment and psychological distress among SLE patients in distressed and non-distressed relationships. In other words, how does supportive and unsupportive behavior affect psychosocial adjustment and psychological distress in non-distressed and distressed relationships?

Predictors of Psychosocial Adjustment & Psychological Distress

SLE patients were divided into two groups based on the RDAS cutoff score (48) for delineating distressed from non-distressed couples, 0 = distressed ($n = 30$) and 1 = non-distressed ($n = 59$). Patient race and family income were included in these analyses as demographic variables because of significant correlations with these outcomes. The dependent variables were
again psychosocial adjustment, as measured by the PAIS-SR, and psychological distress, as measured by the SCL-90-R. In addition, disease activity was used as a covariate. Patient race and income were entered into step one, followed by disease activity in step two, partner supportive behaviors in step three, and partner unsupportive behaviors in step four.

**Non-distressed relationships and Psychosocial adjustment**

For women in non-distressed relationships, the model accounted for 21% (adj R²) of the variance in psychosocial adjustment \[ F(5, 45) = 3.62, p<.001 \]. Again, disease activity was the only significant predictor accounting for 15% of the variance in adjustment (see Table 4.7). Patient race and income, and partner supportive and unsupportive behaviors were not significant predictors of psychosocial adjustment.

**Distressed relationships and Psychosocial adjustment**

For women in distressed relationships, the model explained 60% (adj R²) of the variance in psychosocial adjustment \[ F(5, 23) = 9.47, p<.001 \]. However, disease activity was the only significant predictor accounting for 38% of the variance in adjustment (see Table 4.7). Patient race and income, and partner supportive and unsupportive behaviors did not significantly predict psychosocial adjustment.

**Non-distressed relationships and Psychological distress**

For women in non-distressed relationships, the model explained 33% (adj R²) of the variance in psychological distress \[ F(5, 45) = 5.86, p<.001 \]. Disease activity (14%) and partner unsupportive behaviors (7%) were the only
significant predictors of psychological distress (see Table 4.8). Patient race and income, and partner supportive behaviors did not contribute to psychological distress.

**Distressed relationships and Psychological distress**

For women in distressed relationships, the model explained 59% (adj R²) of the variance in psychological distress \( F(5, 23) = 9.10, p < .001 \). Disease activity (23%), income (19%), and partner unsupportive behaviors (6%) were the only significant predictors in the model (see Table 4.8). Supportive behaviors and patient’s race did not contribute to the prediction of psychological distress.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-distressed Relationships (n = 51)</th>
<th>Distressed Relationships (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Race&lt;sup&gt;a&lt;/sup&gt;</td>
<td>-.22</td>
<td>-.16</td>
</tr>
<tr>
<td>Family Income&lt;sup&gt;b&lt;/sup&gt;</td>
<td>-.01</td>
<td>-.08</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease Activity</td>
<td>.35&lt;sup&gt;*&lt;/sup&gt;</td>
<td>2.42</td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive Behaviors</td>
<td>.18</td>
<td>1.22</td>
</tr>
<tr>
<td>Step 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsupportive Behaviors</td>
<td>.23</td>
<td>1.77</td>
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**Full Model Statistics**

<table>
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<tr>
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</thead>
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<tr>
<td>Multiple R</td>
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<td>.820</td>
</tr>
<tr>
<td>Adjusted Multiple R²</td>
<td>.207</td>
<td>.602</td>
</tr>
<tr>
<td>F (df1, df2)</td>
<td>3.615 (5, 45)&lt;sup&gt;**&lt;/sup&gt;</td>
<td>9.469 (5, 23)&lt;sup&gt;***&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note: ß = standardized beta coefficient for full model.  
<sup>a</sup>Coded as 1 = Caucasian, 0 = Other.  
<sup>b</sup>Coded as 1 = ≥ $40,000, 0 = < $40,000.  
<sup>*</sup>p<.05, **p<.01, ***p<.001

Table 4.7: Regression table predicting psychosocial adjustment in distressed and non-distressed relationships
<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-distressed Relationships (n = 51)</th>
<th>Distressed Relationships (n = 29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ß</td>
<td>t-value</td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Race&lt;sup&gt;a&lt;/sup&gt;</td>
<td>-.19</td>
<td>-1.56</td>
</tr>
<tr>
<td>Family Income&lt;sup&gt;b&lt;/sup&gt;</td>
<td>-.08</td>
<td>-.57</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td>.23***</td>
</tr>
<tr>
<td>Disease Activity</td>
<td>.42**</td>
<td>3.15</td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td>.00</td>
</tr>
<tr>
<td>Supportive Behaviors</td>
<td>.08</td>
<td>.60</td>
</tr>
<tr>
<td>Step 4</td>
<td></td>
<td>.07*</td>
</tr>
<tr>
<td>Unsupportive Behaviors</td>
<td>.28*</td>
<td>2.30</td>
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**Full Model Statistics**

<table>
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<td>.628</td>
<td>.815</td>
</tr>
<tr>
<td>Adjusted Multiple R²</td>
<td>.327</td>
<td>.591</td>
</tr>
<tr>
<td>F (df1, df2)</td>
<td>5.858 (5, 45)**</td>
<td>9.104 (5, 23)**</td>
</tr>
</tbody>
</table>

Note: ß = standardized beta coefficient for full model. <sup>a</sup>Coded as 1 = Caucasian, 0 = Other. <sup>b</sup>Coded as 1 = ≥ $40,000, 0 = < $40,000. *<i>p</i> < .05, **<i>p</i> < .01, ***<i>p</i> < .001

Table 4.8: Regression table predicting psychological distress in distressed and non-distressed relationships.
CHAPTER 5

DISCUSSION

This study investigated the associations between relationship adjustment and partner supportive and unsupportive behavior among women with lupus in terms of psychosocial outcomes. Unfortunately, partner support and relationship adjustment have remained largely separate in the literature and the concepts have rarely been examined together (Acitelli, 1996). The objectives for this study were: 1) to identify the psychosocial adjustment to illness and psychological distress among SLE patients, and 2) to assess if partner support and relationship adjustment interact in predicting psychosocial outcomes among SLE patients. This chapter will begin by discussing the psychosocial outcomes among SLE patients. Next, associations found in this study between relationship adjustment and partner support will be reviewed. Then, limitations of the study will precede suggestions for future research. Finally, clinical implications for marriage and family therapists will be outlined.

Psychosocial Outcomes in Lupus Patients

Factors in Psychosocial Adjustment

Overall, the majority of this lupus sample demonstrated high levels of psychosocial adjustment. Although some domain scores were elevated such as, vocational environment and psychological distress, possible explanations
could include having to change career goals as a result of lupus or increased anxiety levels related to possible progression of the disease. Elevations on the healthcare domain could result either from the difficulty patients have understanding their disease because of the unpredictable nature or the frustration working with medical staff who are uninformed about lupus. In addition, patients are more than likely to have missed activities with friends and families due to symptoms associated with lupus, which could explain the higher scores on the social environment domain.

**Factors in Psychological Distress**

In general, this sample of lupus patients exhibited a moderate amount of psychological distress. Elevations were found on the somatization, obsessive-compulsive, depression, and psychoticism subscales. However, these subscales include items assessing distress that overlap with possible symptoms of lupus. For example, on the obsessive-compulsive subscale items such as concentration and memory difficulties are included, but elevated scores could also result from complications with medical treatment (e.g., corticosteroids). In addition, items such as ‘experiencing low energy’ and ‘everything is an effort’ are included on the depression subscale, which could confound lupus patients’ known levels of fatigue.
Associations between Relationship Adjustment and Partner Support

Preliminary Analyses

Patient’s Disease Activity

There was no significant difference between distressed and non-distressed relationships in terms of patient’s disease activity, which means their levels of symptomology were similar. For the patients in distressed relationships, disease activity was associated with partner unsupportive behaviors but this was not the case with non-distressed relationships. It could mean that patient’s symptoms in unhappy relationships elicit more unsupportive behaviors, which in turn, furthers disease activity. The discrepancy in supportive behaviors could also mean that patients in distressed relationships experience unsupportive behaviors, thus feeling more isolated and more distressed with their partner, which may lead to more vulnerability to the disease. It is also likely that high levels of disease activity could result in a decrease in needed “couple time” or intimacy causing levels of relationship distress to increase. For the patients in non-distressed relationships, disease activity was correlated with partner supportive behaviors, which may suggest that flare-ups lead to more support from spouse. In addition, disease activity was related to both psychosocial outcomes.

Patient’s Race and Family Income

Between the distressed and non-distressed relationship groups, significant differences were found for patient’s race but not for family income. Minorities were more represented in the distressed group, than the non-
distressed. Overall, the sample was relatively wealthy with little variation. Patient’s race was only significantly associated with partner support for the non-distressed group, but this could be more of a limitation to the sample than a true finding. Family income was negatively related to partner supportive behavior in the non-distressed group and to psychological distress in the distressed group. It is possible that couples in non-distressed relationships with more income are secure in relying on their external resources, rather than engaging in supportive behaviors.

**Partner Supportive and Unsupportive Behaviors**

Differences were found between the distressed and non-distressed relationships in terms of partner supportive and unsupportive behavior. Partner supportive behaviors were not related to any psychosocial outcomes in either group, but unsupportive behaviors were related. This seems to support the fact that it isn’t how “nice” you are rather how “not nice” you are that may make a difference (Ewart, Taylor, Kraemer, & Agras, 1991). Interestingly enough, partner unsupportive behaviors were related to both psychosocial outcomes in the distressed group but only to psychosocial adjustment in the non-distressed group.

**Relationship Adjustment**

Relationship adjustment was associated with both partner supportive and unsupportive behavior for the non-distressed group. However for the distressed group, only partner supportive behavior was related to relationship adjustment. This could mean that couples in non-distressed relationships can see their
partner’s encouragement in order to help look past conflict or unmet needs. Also, couples in distressed relationships may be benefiting from supportive behavior.

**Interaction of Relationship adjustment and Partner Support**

The interaction between relationship adjustment and partner support was not found in this sample when examining either psychosocial adjustment or psychological distress. Possible reasons for not detecting an interaction in this sample were highlighted in Chapter 4, but will be discussed as a limitation of this study. It appears that the interaction term could be suppressing partner unsupportive behavior. These findings may suggest that unsupportive behavior moderates the relationship between relationship adjustment and psychosocial outcomes.

**Post Hoc Analyses**

When comparing the non-distressed and distressed relationship groups, significant differences were found on all variables except disease activity and patient race, which indicates that the context of the relationship is important. That is, there is something significant about a couple’s level of relationship adjustment in terms of how they interact with each other (e.g., support) and how they react (e.g., psychosocial outcomes). For example, this could support those patients viewing their relationships as non-distressed benefit from the buffering effect against unsupportive behaviors (Cohen & Wills, 1985).

It does not appear that partner supportive behaviors contributed to predicting either psychosocial outcome. When predicting psychological
distress, partner unsupportive behavior was a significant predictor for both
distressed and non-distressed relationship groups.

In terms of income being a predictor, it was only significant when
predicting psychological distress in distressed relationships. Again, this could
be an artifact of the sample rather than an accurate representation of the
relationships income has with these variables. However, there is also the
possibility that distressed couples do not have access to other resources (e.g.,
psychotherapy, external supports) due to their limited income which could
alleviate some of their psychological distress.

Limitations of the Study

Despite working with an existing dataset, important information was
gained in this study, however there are several limitations that should be
addressed. The first limitation is the small sample size, especially in the post-
hoc analyses. The size of the sample may have had an effect on the power
that was available to find significant interactions that could have existed. This
potentially limited the ability to accurately assess the associations between
partner supportive and unsupportive behaviors and relationship adjustment.
Therefore, caution should be taken when generalizing from these results.

A related limitation was the fact that the sample was fairly homogenous.
The majority of patients were Caucasian with relatively high incomes in happy
relationships. The incidence of SLE is 2 to 3 times higher in African-Americans
than Caucasians (McCarty et al., 1995) and since this sample was comprised of
a majority of Caucasians, a gap remains in the literature regarding possible
associations between partner support and relationship adjustment in ethnic minorities.

A third limitation was the use of individual data as opposed to couple data. In order for the field of marriage and family therapy to further our understanding of the relational processes between partners, dyadic assessments must be implemented. Having both perspectives on these variables may have resulted in different associations. It may also be that perception is reality for SLE patients.

Recommendations for Future Research

Based on the findings of this study, there appears to be two main avenues for future research. First, psychosocial researchers must begin to place more of an emphasis on including lupus patients in future studies. The fact remains that more people have been diagnosed with lupus in the United States than AIDS, multiple sclerosis, and cystic fibrosis combined (Lupus Foundation of American, 1996). The lack of social science research including lupus populations brings light to the lack of funding for autoimmune diseases in the social sciences for more popular illnesses such as, breast cancer and HIV. Furthermore, because of the unpredictability of symptoms and difficulty delineating psychological distress from disease characteristics, it is difficult to generalize findings from other chronic illnesses.

The second avenue for future research is furthering the field of marriage and family therapy’s understanding of the interpersonal processes between relationship adjustment and partner support. First, researchers need to be clear
when using concepts such as, relationship adjustment, quality, or satisfaction, and social support versus partner support, and dyadic coping. This is an argument made throughout the social support literature (Burman & Margolin, 1992; Coyne & DeLongis, 1986). Research also needs to assess both the supportive and conflictual aspects of relationships. The trend in the social support literature is to focus on one aspect such as, stress-buffering, social strain, or main effects, etc.

Next, relationship outcomes need more attention. The impact of social support and relationship adjustment on health has been well-established (for a review, see Burman & Margolin, 1992; Kiecolt-Glaser & Newton, 2001); however, it is likely that relationships are bi-directional. Therefore, assessment and research design should incorporate transactional models to determine how these mechanisms interact. For example, we need to include more investigations looking at the moderating or mediating effects of partner support in terms of relationships and psychosocial outcomes.

Along the lines of assessment and research design, psychometricians and MFT researchers need to collaborate to develop assessments of dyadic variables. Assessments at the dyadic level will help further our investigation into the processes currently limited by our individual level of measurement. Factors related to the social context of research participants need to be addressed. Most of the samples in the literature are homogenous and thus limited in generalizability and practical implications. Differences in terms of race, ethnicity, social class, and gender are important variables that remain
underinvestigated by the current focus of both the social support and relationship adjustment literatures.

Finally, Revenson (2002) suggests that interventions should broaden their focus. Currently, steps to intervening with unsupportive behaviors or how to get partners to be more supportive are the trend. However, interpersonal processes between partners are part of the answer to how all of these factors interact, suggesting that an increase in process research is needed. In addition, MFT clinical interventions should inform our research, just as our research informs our therapy. This may require marriage and family therapists to concede that couples’ interventions are not always indicated or effective for chronically ill couples. Rather, a systemic approach to dyadic processes with interventions at many layers may be more successful.

Clinical Implications for Marriage and Family Therapists

“Be careful not to jump to implications because we have ‘thin’ explanations for ‘thick’ problems” (Coyne, 2002). The clinical implications of the social support literature, especially with lupus patients, are nonexistent. Most studies examine factors correlated with support or relationship adjustment without understanding what makes a difference in the lives of the chronically ill. Four implications for marriage and family therapists will be outlined.

First, therapists should understand the overlap of symptoms in lupus and depression. Not every client with lupus will be clinically depressed, and thorough assessment of depression should distinguish physical disease from mental disorder. In order to efficiently diagnose the symptoms and effectively
prepare a treatment plan, therapists may utilize the Profile for Mood States to assist in differentially diagnosing clinical depression (POMS; McNair, Lorr, & Droppelman, 1992). The POMS can take into account symptoms experienced due to an illness versus meeting criteria for clinical depression.

Distinguishing clinical depression from physical symptoms of lupus is especially important when patients are seeking MFT for other issues besides adjusting to their illness. Doherty and Simmons (1996) surveyed marriage and family therapists regarding treatment and found that adjustment disorders were the number one diagnosis treated by this sample of therapists. Because the onset of lupus typically occurs for women in the childbearing years, chances are increased that individuals could be seen for adjustment to marriage or transition to parenthood. Clinicians should make it a standard practice to assess for all chronic illnesses in the intake and assessment phase of therapy in order to have an accurate representation of the family system.

The second implication for clinical practice is an awareness of the patient as part of a system and therefore identified with more than the symptoms of lupus. In other words, SLE patients are also parents, siblings, friends, and partners. Thoits (1991) suggests that individuals can get distressed primarily when a central part of identity is being threatened. Again, this is important with respect to lupus because of the age at onset of illness typically occurs during childbearing years. If a young mother is diagnosed with lupus and cannot be the primary caregiver of the family during periods of flare-ups, she may resent her husband’s efforts. Marriage and family therapists can help the couple
negotiate roles and develop flexibility needed to move back and forth during periods of flare-ups and remissions.

The third implication for marriage and family therapists is the awareness of the cascading effect couples use to cope with stress (Bodenmann, 2002). In a study of healthy couples in Sweden, findings demonstrated that coping with a stressful event was first met by an individuals’ effort to cope, followed by a partner/spouse, then friends, and finally professional help. This cascading effect suggests there is some conscious choice of who is chosen to help cope with a stressful event. After repeated attempts to solicit support from a spouse is met with tension or more stress, lupus patients may choose to assign the role of caregiver to another family member or friend. Therefore, any subsequent supportive attempts made by the partner may be seen as distressing. As a result, marriage and family therapists could assist patients in deciding whether their preference is for their partner to fill the role of primary caregiver. Next, the expectations about their role, as caregiver or simply spouse, must be made clear. This includes delineating the differences between supportive and unsupportive behaviors, as experienced by the patient. Again, it may be that therapists should encourage less “date nights” (i.e., supportive behavior) when what the patient may need is less tension about not feeling able to go out (i.e., unsupportive behavior).

The fourth implication for therapists is along the same line of delineating supportive and unsupportive behaviors. Coyne (2002) suggests that therapist and researchers not confuse unsupportive behaviors as a skills deficit.
Therapists often like to increase support in couples by teaching skills such as active listening or empathy. However, this practice may ignore the option patients have in choosing whether they want their spouse to fill the role of primary caregiver. More importantly, teaching couples to be more supportive ignores the fact that more support is not always helpful while also failing to address the unsupportive behaviors in the relationship. Marriage and family therapists need to spend time directly addressing the unsupportive behaviors occurring in the relationship.

Another alternative is suggested by John Gottman (1999) in his book, *The Seven Principles for Making Marriage Work*. He recommends that for every negative interaction between couples, there needs to be at least five positive interactions. Therapists should assist couples in a discussion about what is deemed supportive and unsupportive to make each partner aware of the other’s perspective on their behavior.

Conclusions

An interaction effect between relationship adjustment and partner support was not found; however, the findings suggest that the context of the relationship does add to our knowledge in terms of partner support. For SLE patients in both distressed and non-distressed relationships, it is not how helpful the partner is, but rather how unhelpful they are that relates to psychosocial outcomes. In this regard, research and clinical intervention must influence one another to promote an effective balance between health, support, and relationship adjustment. As marriage and family therapy researchers, attention
must continue to investigate the role of both supportive and unsupportive behaviors in chronic illnesses.
REFERENCES


APPENDIX A:
PARTNER RESPONSE TO ILLNESS QUESTIONNAIRE
Below is a list of ways that people sometimes respond to their partner when she is ill. Please rate each of the following responses in terms of:

A) How often your partner did it during the past month, and
B) How helpful it was to your dealing with your illness and treatment.

If your partner Never or Rarely engaged in the listed behaviors, please rate how helpful it was that your partner Never or Rarely did those things. This means, for any statements you give a 1 or a 2 for your rating of how often your partner did those things, you must think about how helpful it was that they did not or rarely did those things.

Please use the following scales.

A. How often? B. How helpful?
1 = Never 1 = Very unhelpful
2 = Rarely 2 = Somewhat unhelpful
3 = Occasionally 3 = Neither helpful nor unhelpful
4 = Frequently 4 = Somewhat helpful
5 = Always or almost always 5 = Very helpful

For your convenience, you may want to tear off this page to use the scales for the following pages.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1. Avoided talking about the illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Down-played the seriousness of the illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Told her that she would get better</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Took over some of her responsibilities (e.g. child care, meals, housework)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Pointed out her mistakes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Attributed problems to the illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Told her what to do all the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8. Spent more time with her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. Listened to her thoughts and feelings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10. Complained about her to someone else</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11. Ignored her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12. Showed more physical affection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13. Didn't help with things at home when she needed it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14. Refused to talk to her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15. Threatened to leave her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16. Became involved in learning about the illness and treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17. Became involved in decisions about her treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>18. Encouraged her to do things about her illness</td>
</tr>
</tbody>
</table>

79
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>_____</td>
<td>_____</td>
<td>19. Got angry with her for not taking care of herself</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>20. Blamed her for getting ill</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>21. Encouraged her to feel that she would overcome the illness</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>22. Showed concern about her pain</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>23. Did not respond to her sexual advances</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>24. Helped her to get around</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>25. Became irritated with her</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>26. Helped take care of her physical needs (e.g. ointments, medications)</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>27. Reassured her about the future</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>28. Became upset when she talked about her fears</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>29. Pushed for sex even when she wasn't in the mood</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>30. Reassured her about her physical attractiveness</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>31. Became upset with her when she couldn't do something that she used to do</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
<td>32. Had a negative reaction to side effects of her treatment (e.g. weight gain, nausea, nervousness)</td>
</tr>
<tr>
<td>---------------</td>
<td>----------------</td>
<td>----------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>33. Told her when she was doing something well</td>
</tr>
<tr>
<td></td>
<td></td>
<td>34. Criticized her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>35. Said that I loved her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>36. Reassured her that what she wanted to do was right</td>
</tr>
<tr>
<td></td>
<td></td>
<td>37. Helped her to understand something</td>
</tr>
<tr>
<td></td>
<td></td>
<td>38. Treated her like a child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>39. Said that I would always be around for her</td>
</tr>
<tr>
<td></td>
<td></td>
<td>40. Used humor to cheer her up</td>
</tr>
<tr>
<td></td>
<td></td>
<td>41. Encouraged her to get more information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>42. Tried to maintain normal routines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>43. Didn't want to let her make decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>44. Encouraged her to be strong</td>
</tr>
<tr>
<td></td>
<td></td>
<td>45. Acted as if nothing happened</td>
</tr>
<tr>
<td></td>
<td></td>
<td>46. Encouraged her to prepare for the worst</td>
</tr>
</tbody>
</table>
APPENDIX B:
BACKGROUND INFORMATION SHEET
Lupus and Partner Relationships Study
Background Information Sheet

We would like to learn more about your background and your experience with lupus. Please answer these questions as they apply to your current situation.

1. Age of patient _______ Date of Birth ___________

2. Age of partner _______ Date of Birth ___________

3. Gender of patient:       Male  Female

4. Gender of partner: Male  Female

5. Race of patient:
   ______ African-American
   ______ Caucasian
   ______ Asian
   ______ American-Indian
   ______ Hispanic
   ______ Other _______________________________

6. Race of partner:
   ______ African-American
   ______ Caucasian
   ______ Asian
   ______ American-Indian
   ______ Hispanic
   ______ Other _______________________________

7. Date lupus first diagnosed (Month/Year) ________/________
   Date symptoms first appeared (Month/Year) ________/________

8. Did you receive any alternative diagnoses prior to the diagnosis of lupus?
   ______ Yes       ______ No

   If so, what diagnoses did you receive?
   ____________________________________________________________________
9. How long have you been in a relationship with your current partner?

______ Years ______ Months

10. Are you and your partner:

_______ Married
_______ Dating
_______ Engaged
_______ Remarried
_______ Living Together
_______ Common-Law (at least 7 years living together)
_______ Other

11. Patient's highest level of formal education completed:

_______ High School Diploma
_______ Technical College
_______ College Graduate
_______ Master's
_______ Law Degree
_______ Doctorate
_______ Other (please specify)

12. Partner's highest level of formal education completed:

_______ High School Diploma
_______ Technical College
_______ College Graduate
_______ Master's
_______ Law Degree
_______ Doctorate
_______ Other (please specify)

13. Number of children (including step-children)? ________________
Ages? __________________

14. Number of children still living in the home? ________________
15. Employment status of patient?

______ Part-time
______ Full-time
______ Retired
______ Homemaker
______ Seeking work
______ Disabled
______ Other (please specify)

16. Employment status of partner?

______ Part-time
______ Full-time
______ Retired
______ Homemaker
______ Seeking work
______ Disabled
______ Other (please specify)

17. Occupation of patient?


18. Occupation of partner?


19. Yearly gross family income?

______ < $10,000
______ $10,000 - $20,000
______ $20,000 - $40,000
______ $40,000 - $60,000
______ $60,000 - $80,000
______ $80,000 - $100,000
______ > $100,000

20. Are either you or your partner currently a member of a lupus or an arthritis organization of any type?

______ No
______ Yes. Which one(s)?

21. Who is a member of this/these organizations?

______ You
______ Your partner
______ Both
22. Has your treating physician given you information about lupus?
       _______Yes
       _______No

       If yes, what kind of information were you given?

23. Has he or she given your partner any information about lupus?
       _______Yes
       _______No

       If yes, what kind of information was given?

24. Have you or your partner ever been involved in any type of educational or support group for lupus?

       If so, When? (Month/Year - Month/Year) ______________________

       and Where? ______________________

       What kind of group was it?

25. How well informed would you say you are about the illness?

       _______Very well informed
       _______Well informed
       _______Poorly informed
       _______Very poorly informed

26. How well informed would you say your partner is about the illness?

       _______Very well informed
       _______Well informed
       _______Poorly informed
       _______Very poorly informed

27. Has anyone else in your family been diagnosed with lupus?

       _______No       _______Yes. Whom? ______________________
28. Are you currently taking any of the following medications for lupus?

- [ ] Aspirin or aspirin derivatives
- [ ] Tylenol or Tylenol-like medications
- [ ] Nonsteroidal anti-inflammatory drugs (NSAIDS)
- [ ] Antimalarials
- [ ] Corticosteroids
- [ ] Immunosuppressants
APPENDIX C:
SYSTEMIC LUPUS ACTIVITY QUESTIONNAIRE
Lupus and Partner Relationships Study  
FLARE - Patient Version

1. In the past month, have you had a lupus flare? 
(A lupus flare is when your lupus gets worse.) 
Please tell me which of the following responses best describes you.

   No, no flare .................. 0 
   Yes, mild flare ............... 1 
   Yes, moderate flare .......... 2 
   Yes, severe flare............ 3

2. In the past month, have you seen a doctor for your lupus? 
   No (0)  Yes (1) → Number of visits ______

2a. In the past month, has your doctor mentioned any change in your kidney function? 
   No (0)  Yes (1) → Is it:  Better (1)?  Worse (2)?

3. In the past month, have you been hospitalized for your lupus? 
   No (0)  Yes (1) → How many days? ______

4. In the past month, did your doctor increase your prednisone dose? 
   No (0)  
   Yes (1)  
   I am not taking prednisone. (8)

5. In the past month, have you had any other medical problems? 
   No (0)  Yes (1) → Describe:__________________________________________
6. Please review the following list of symptoms. In the past month, how bad has each of these symptoms been? Please circle a number for each symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>MILD</th>
<th>MODERATE</th>
<th>SEVERE</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Lost weight without trying</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>b) Fatigue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>c) Fevers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>d) Sores in mouth or nose</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>e) Rash on cheeks (shaped like butterfly)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>f) Other rash (Where? ________________)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>g) Dark blue or purple spots you could feel on your skin</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>h) Rash or feeling sick after going out in the sun</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>i) Bald patches on scalp, or clumps of hair on pillow</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>j) Swollen glands</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>k) Shortness of breath</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>l) Chest pain with deep breath</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>m) Fingers or toes turning dead white (Raynaud's)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>n) Stomach or belly pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>o) Numbness or tingling in your arms or legs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>p) Seizures</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>q) Stroke</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>r) Forgetfulness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>s) Feeling depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>t) Unusual headaches</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>u) Muscle pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>v) Muscle weakness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>w) Pain or stiffness in joints</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>x) Swelling in joints</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

7. Please rate the disease activity of your lupus DURING THE PAST MONTH on the scale below, where 0 is no activity and 10 is the most activity. (Check the box for your most active day.)

<table>
<thead>
<tr>
<th>No Activity</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

Most Activity
In the past month, has your lupus been:

Much better .................. -2
Better .......................... -1
Same ............................ 0
Worse ........................... +1
Much worse .................... +2