Concordance between Need and Receipt of Social Support, Independence and Associations with Well-Being in Women with Systemic Lupus Erythematosus

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science Institute of Health Policy, Management and Evaluation University of Toronto

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ABSTRACT

Women living with Systemic Lupus Erythematosus (SLE) have the potential for increased support needs due to SLE's often severe and unpredictable symptoms. However, they may also strive to maintain their independence. A cross-sectional survey examined need for and evaluations of three types of social support in five diverse life domains and their associations with well-being and disease appraisals, demographic, clinical and social network characteristics. One hundred sixty-three (163) women, aged 19 - 88, were surveyed, drawing on an existing clinical cohort. Across domains, occurrences of concordance between the respondents' reported need for support and the support they received were associated with significantly greater well-being than occurrences of discordance. These findings held regardless of whether respondents were independent or dependent on others. This study highlights the need for interventions that emphasize optimizing social support - balancing independence and support needs - rather than assuming that maximizing support is always desirable.

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1.0 INTRODUCTION

1.1 Introduction

Systemic Lupus Erythematosus (SLE or lupus) is an autoimmune disease with the potential to impact many organ systems, such as the skin, joints, kidneys, heart, and brain, and which most commonly affects women. It is life-threatening if not managed appropriately and remains associated with poor health status despite treatment. The nature of SLE creates unique challenges for women living with the disease in trying to manage its variable and unpredictable presentation and course, along with the disability and functional limitations that frequently arise (Murphy *et al.*, 1998; Sutcliffe *et al.*, 1998; Da Costa *et al.*, 1999).

Social support has long been studied as a construct with the potential to mitigate the relationship between a stressor, such as living with a disease, and mental and physical well-being outcomes. In the general population, lack of social support is associated with increased vulnerability to mental health problems such as depression (Shumaker & Brownell, 1984; Winefield *et al.*, 1992; Dumont & Provost, 1999). Researchers have examined both main effects of social support and interaction (buffering) effects of support. Some studies in chronic illness suggest that social support contributes to greater psychological well-being irrespective of the level of life stress (i.e., a main effect of support) [e.g., La Rocco & Jones (La Rocco *et al.*, 1978); Lin, Simeone, Ensel, & Kuo (Lin *et al.*, 1979); Williams, Ware, & Donald (Williams *et al.*, 1985)]. Others have found that informal support from others is most relevant at high levels of stress and can buffer or protect a person from the mentally or physically pathogenic effects of high stress

(Cohen & Wills, 1985). The present study does not focus on whether there are buffering or main effects of support, but rather examines evaluations of diverse types of support in different domains of life, whether it is perceived as needed or desired, and its associations with well-being and disease appraisals.

It is important to recognize that more support may not always be better, and that increases in social interaction might not always be protective. A review of support studies by Cohen and Wills (1985) showed that social support protected against negative psychological outcomes only if the support resource matched the needs produced by the stressor. Additionally, attempts to increase well-being through social support interventions have had mixed results (Cowan & Cowan, 1986; Lavoie, 1995; Burgeois et al., 1996; Helgeson & Cohen, 1996), highlighting that the relationship between social support and health is complex. Current global measures of support, particularly those often employed in chronic disease cohorts, do not capture this complexity. For example, appraisals of social support are important and can vary, not only between individuals in terms of whether support is needed, but also within an individual in the type, timing and domain of support, and whether it is perceived as satisfactory (Barrera, 1981; Sarason et al., 1983; Cohen & Syme, 1985; Gottleib & Bergen, 2010). Although these concepts have not been quantitatively studied in SLE, we know that women living with the disease are concerned about their social network, social support and feelings of independence. For example, participants in qualitative studies report:

"[SLE] makes me feel dependent where I have never been dependent." (Baker & Wiginton, 1997, p. 133)

"I am so good at helping other people...I don't like the idea that I am the one who needs a break." (Miles, 2009, p. 4)

"My friends who know I have lupus see me in a different light; they see me as very fragile. I don't like any special treatment." (Ow *et al.*, 2011, p. 905)

"I don't have a lot of friends...[people my age] are so cruel." (Howe, 2009, p. 42)

"It's not that I couldn't do anything, it's that [my husband] didn't want me to." (Grant, 2001, p. 326)

"I have a fear of losing my independence." (Baker & Wiginton, 1997, p. 133)

In fact, many of the studies that were part of a recent systematic review of qualitative SLE studies reported the presence of feelings that could impact close social relationships, such as being self-conscious around others, limited participation in social activities, loss of sex drive, fearing rejection, feeling like a burden, having too much pain or fatigue to visit with friends, feeling like others think one is exaggerating or fabricating symptoms, and misunderstanding about SLE being a contagious disease (Sutanto et al., 2013). Participants additionally reported that they felt fearful of losing their independence. These individual feelings about social support and independence may be associated with well-being, but they have not been examined in detail. Psychological well-being in those with SLE is generally poorer than that of the general population and those with other chronic illnesses, as described in a review of the relevant literature by McElhone et al. (2006). Furthermore, there is existing evidence for a relationship between social support and well-being in SLE (Karlson et al., 1997; Dobkin et al., 1999; Sutcliffe et al., 1999; Alarcon et al., 2001; Failla et al., 2009; Zheng et al., 2009; Mazzoni & Cicognani, 2011). This study examines the complexity of social support by examining perceptions of the need for support and the support received by women with SLE across diverse domains, the appraisals or evaluations of this support in terms of maintaining independence, and

the relationship of support and independence to psychological well-being and disease appraisals.

1.2 Consideration of Sex and Gender Differences

SLE is a disease that overwhelmingly affects women, with a ratio of approximately nine women for every one man with the disease (Pons-Estel *et al.*, 2010). Further, there is evidence for differences in the pathogenesis and outcomes in SLE due to both sex and gender (Inman, 1978; Soto *et al.*, 2004; Yacoub, 2004; Croslin & Wiginton, 2011; Schwartzman-Morris *et al.*, 2012). These differences may be due to differences in sex hormones, other biological features, societal gender norms, parental influence, or other factors, with it being likely that a combination of variables is at play. For example, modern changes in participation in roles like work, caregiving, and family responsibilities have had considerable impacts in the activities of both men and women (Bird & Rieker, 2008). Because this research will rely on recruitment from an existing cohort of SLE patients that is approximately 90% female, and because recruiting enough men to appropriately examine sex and gender differences will be difficult, the present study focuses on a sample of women only.

1.3 Rationale for the Study

Most of the available social support scales measure presence or absence of potential support resources (e.g. close friends), with the assumption that support is provided by these individuals and appraised positively by the recipient. However, it is possible that there are times when the receipt of help is needed, but is not received; or when it is not needed, but is received. Support received may also be appraised positively or negatively

by individuals in terms of its helpfulness or desirability. A mismatch, or discordance, between the receipt of support and the personal evaluation of that support may exist in one or more domains of life (e.g., household activities, caregiving, employment) and for the types of support provided (e.g., emotional support, physical help with activities). Past research on social support in SLE has utilized global scales and analyses have focused on the relationships between total available support and a variety of health-related factors. Findings have been variable in terms of the associations between social support and both clinical and social outcomes. We hypothesize that this could be due to a need for greater detail about the perceived need and actual receipt of support, as well as appraisals of the value of the support provided. Specifically, there may be stronger positive relationships between support and well-being when the receipt and appraisals of support are concordant rather than discordant.

1.4 Overall Aim and Objectives

The ultimate goal of the present study is to identify strategies to improve the quality of life of women with SLE by addressing gaps in the literature on the meaning of support and by contributing a more detailed and complex view of social support and well-being in a sample of women with SLE. Greater depth of understanding of support needs is important in order to meet the needs of women with SLE, to evaluate existing self-management interventions, and to inform new ways to help women with lupus manage their disease and participate fully, and as desired, in the areas of life that they value most.

1.4.1 Hypothesis

It is hypothesized that there will be differences in experiences with receiving informal support and in evaluations of the support received, not only across women with SLE, but also within the same woman across differing types of support and domains of activity (e.g., household activities, employment, recreational activities). Regardless of the amount of support, if there is discordance between the support desired or needed and the support that is received, it is hypothesized that women will appraise the support more negatively and, in turn, these appraisals will be associated with poorer well-being and disease appraisals than those with concordant supportive relationships.

1.4.2 Study Objectives

The specific objectives of the study are:

1. To better understand the support experiences of women with lupus and a potential discordance between the need for and receipt of different types of social support.

Social support experiences will be examined in terms of whether or not support is received, and whether or not each individual evaluates this support as satisfactory. These experiences will be examined in five domains of life: employment and education, family relationships, recreation and social activities, personal finances, and household maintenance. Within each of these domains, three types of support will be examined: instrumental, emotional, and informational support.

Based on the receipt and evaluation of support in different life domains and for different support types, participants will be grouped into the following

independence groups: Independent, Dependent, Not Independent, Under-Supported and Imposed Dependence (described in detail in **section 2.3.2**). These groups will be further divided into either concordant or discordant relationship types, based on whether the receipt of support is deemed by the individual to be in concordance with their individual needs or desires for support. The domains and support types will be described in terms of the distribution of individuals to: a) independence groups; and b) concordant or discordant support relationships. The number of discordant supportive relationships per individual will also be described.

The women studied are hypothesized to show variability in terms of perceived independence, and the concordance or discordance between what is needed and received. This variability will be seen both between individuals and within an individual across life domains and support types.

2. To examine the associations of independence grouping and discordant relationships with well-being and disease appraisals.

It is hypothesized that Independent individuals will have greater perceived wellbeing than the Dependent, Not Independent, Under-Supported, and those in a position of Imposed Dependence; Dependent individuals will have greater wellbeing than the Not-Independent, Under-Supported, and Imposed Dependence groups because they still deem their needs or desires for support to be met. Further, it is hypothesized that more concordant support relationships in an individual's life will be associated with better well-being and disease appraisals.

3. To examine the demographic, health, and social network characteristics that may relate to membership in each independence grouping.

Demographic factors examined in this research are age, marital status, annual household income, education, and current work status. Health characteristics include disease duration, current disease activity, recent flares, pain, fatigue, and symptom severity since diagnosis. Social support is assessed in terms of a standardized measure of available support, and social networks are assessed in terms of the size of an individual's network and perceived composition and strength of associations in the networks. It is hypothesized that poorer demographic (socio-economic) and clinical variables will be associated with less independence. Further, it is hypothesized that greater availability of support and stronger, larger social networks will be associated with dependence.

1.5 Structure of this Thesis

To address the study objectives, this thesis will be structured in the following way: *Chapter Two: Background and Supporting Literature*. This chapter reviews the literature relevant to the concepts presented in the thesis, noting the current gaps in research. SLE is described with attention to the symptoms and difficulties it creates for those living with the disease. The conceptual literature pertaining to social support and independence is also presented, as well as the relevant well-being literature relevant to SLE. Four surrogate measures of the concept of well-being and disease appraisals used in previous research are examined, as well as literature pertaining to different areas of life affected by

SLE. These diverse areas are synthesized into a conceptual framework that is used to guide the selection of variables and subsequent analyses used in this thesis.

Chapter Three: Methodology. This chapter presents the study design, strengths and limitations of the design and efforts taken to avoid bias. Identification and recruitment of study subjects, and recording and quality control of study data is also provided. Variables used in the study are defined, and measures to capture these variables are described. Finally, statistical analyses used to answer study objectives are outlined.

Chapter Four: Results. This chapter outlines descriptive analyses of all measures used in the study. Further results are presented in order of the objectives of the study.

Chapter Five: Discussion and Conclusions. Chapter five presents an overall review of the findings of the study, followed by a more in-depth discussion and examination of the results for each objective. The strengths and relevance of the study and its implications for researchers, clinicians and health systems, and patients is discussed, as well as directions for future research and final conclusions.

2.0 BACKGROUND AND SUPPORTING LITERATURE

2.1 Systemic Lupus Erythematosus (SLE)

Systemic Lupus Erythematosus (SLE or lupus) is a systemic autoimmune inflammatory disease that disproportionately affects women, with 80 - 90% of individuals living with the disease being female (Kotzin, 1996; Petri, 2002; Rus & Hochberg, 2002; Lim & Drenkard, 2008). Though still considered life-threatening due to pervasive organ involvement, the survival rate for SLE has increased greatly over time. The 5-year survival reaches up to 95%, partly due to better identification and treatment (Cervera, *et al.*, 2003). However, increased survival brings an increase in disease and disability prevalence (Gladman, 1995; Urowitz *et al.*, 1997; Uramoto *et al.*, 1999; Cervera *et al.*, 2003; Bernatsky *et al.*, 2006; D'Cruz *et al.*, 2007; Khamashta & Hughes, 2007; O'Neill & Cervera, 2010; Pons-Estel *et al.*, 2010), with estimates ranging from 20 to 150 cases of SLE per 100 000 persons (Pons-Estel, *et al.*, 2006). This has resulted in greater attention to the many challenges of living life with SLE .

2.1.1 SLE as a Unique Chronic Illness

SLE is different from many other chronic illnesses in terms of the range, invisibility, and uncertainty of symptoms, as well as the often deleterious effects of treatments for the disease. SLE can present in any organ system with a variety of symptoms and manifestations. Symptoms can vary widely from one patient to another, or within a given patient over the course of her disease (O'Neill *et al.*, 2010; Urowitz *et al.*, 2014). SLE can present as general malaise, fever, fatigue, weight loss, skin rashes, joint inflammation, anemia, inflammation of the lymphatic glands, decreased infection resistance, and

cardiac, kidney, neurological and pulmonary changes (Hochberg, 1997; Peralta-Ramirez *et al.*, 2004; Panopalis & Clarke, 2006; Smith & Gordon, 2010; Toloza *et al.*, 2011; Urowitz *et al.*, 2014). To aid clinical diagnosis and ensure comparability of SLE cohorts, the American College of Rheumatology (ACR) created the ACR lupus classification criteria (**APPENDIX I**). Four of the criteria must be met to be classified as having lupus for research purposes (or 3 criteria with lupus confirmed on skin or kidney biopsy) (Manzi *et al.*, 2005).

SLE presents a challenge to those living with the disease because many of its symptoms can be invisible to others. When an illness does not create overt signs of disease and is not readily evident to others, individuals must decide whether and to whom to disclose the illness. Disclosure can result in greater support and understanding, but it also involves risk. Individuals often express anxiety that negative stereotyping, stigma and even discrimination may accompany disclosure of health problems to others (Joachim & Acorn, 2000; Beckerman, 2011).

Moreover, the uncertainty of a future living with lupus can also be a stressor (Neville, 2003). A study of another chronic illness, diabetes mellitus (Landis, 1996), reported that uncertainty had a strong negative relationship with psychosocial adjustment and feelings of well-being among respondents. SLE has an unpredictable course, even with ongoing and comprehensive disease management. A study of acute increases in SLE-related disease activity, or "flares", in a Canadian cohort found that flares occurred at a rate of 0.55 per person year (Fortin *et al.*, 1998). Flares can result in mental and physical fatigue and can decrease an individual's ability to function.

Further challenges accompany the treatments for lupus. Treatment is an ongoing process that encompasses medications, regular laboratory testing, and clinical evaluation to ensure optimal management. Medications for lupus come with a range of potential side effects that can be detrimental to quality of life, including cytotoxicity, changes in metabolism and body shape, and increased susceptibility to infection (Panopalis *et al.*, 2006; Toloza *et al.*, 2011). Management of complex drug therapies, appointments, and care providers, as well as the financial burden of accessing care, treatment, and living with disability can be challenging.

2.1.2 SLE and Activity Participation Limitations

Activity limitations and disability can result from lupus and its treatments. Limitations can be physical, resulting from arthritis, pain, fatigue or organ damage, and mental or emotional resulting from neuro-psychological dysfunction or reactive depression from living with a chronic illness (Murphy *et al.*,1998; Sutcliffe *et al.*, 1998; Da Costa *et al.*, 1999; Tench *et al.*, 2002; Huang *et al.*, 2007; Xiang & Dai, 2009; Almehed *et al.*, 2010; Katz *et al.*, 2010; Macejova *et al.*, 2013; Al-Dhanani *et al.*, 2014; Mau *et al.*, 2014). Though data is not available for SLE specifically, a review of the US Social Security Disability Insurance (SSDI) program found that 21% of beneficiaries had musculoskeletal and/or connective tissue disorders (including SLE) (Scofield *et al.*, 2008).

Women in their child-bearing years have a greater probability of SLE diagnosis. Sixtyfive percent of SLE patients are diagnosed between the ages of 16 and 55 (Kotzin, 1996; Mok *et al.*, 2000; Dobkin *et al.*, 2001; Schur & Hahn, 2009), a period when roles and activities such as raising children, caring for a family, managing a household and gaining

and, maintaining employment can be complicated or even precluded by the intrusion of chronic illnesses (Karasz & Ouellette, 1995; Devins *et al.*, 2005; Mendelson, 2006; Robinson *et al.*, 2010; Schattner *et al.*, 2010). Following diagnosis with SLE, individuals may face challenges in managing the demands of their day-to-day life (Macejova *et al.*, 2013). Both physical and mental dysfunction can impact negatively on many activities and roles (Hassett *et al.*, 2012), and this may be particularly distressing when it occurs in the areas of life most valued by those with a chronic disease. In a study of 897 SLE patients, 91% of the sample reported a physical inability to participate in at least one life activity (Katz *et al.*, 2008). A more detailed discussion of potential limitations in specific domains and roles is presented later.

2.2 Social Support

Social support refers to the existence or availability of people on whom we can rely, and the assistance they may offer or provide; people who let us know that they care about, value and love us through these actions (Sarason, *et al.*, 1983). A review of community-based studies in the general population found earlier mortality among those with fewer close relationships, including spouses and family members (Berkman & Glass, 2000). The number and types of individuals from whom one may receive support varies between individuals. There is evidence that many women with SLE have unmet needs in trying to manage the difficulties in living with their disease, and that support from health professionals, family, friends, and others can influence health and disease management (Cohen *et al.*, 2000; Rosland *et al.*, 2008). In a needs assessment study of 386 SLE patients, participants stated that their unmet needs included emotional needs, lack of information, and lifestyle limitations (including work and recreational activities)

(Bauman *et al.*, 2006). Additionally, a longitudinal study describing the needs of 233 SLE individuals describes persistently high unmet needs for most of the sample (Moses *et al.*, 2008).

2.2.1 Types of Social Support

Previous research has noted that the type of support received by an individual with an illness is important in predicting positive outcomes (Schroevers *et al.*, 2010). Cohen, Underwood and Gottlieb (2000) describe three types of social support:

- *Instrumental support* includes tangible, practical help and material aid (e.g. money, transportation, childcare and performing household tasks). This type of support is directed toward solving practical problems and may allow more time for an individual to focus on self-care and other areas of life, and to better manage physical and psychological fatigue.
- *Emotional support* includes having a confidante to reassure an individual of their worth, and with whom one can foster attachment and intimacy. This may include discussing feelings, showing sympathy and acceptance, and caring for a person. This type of support is thought to alter the perceived threat of life events, reduce anxiety, and motivate individuals in their self-care efforts.
- *Informational support* includes advice and guidance, such as providing information about resources, suggesting courses of action, and providing advice about the effectiveness of alternative strategies. This increases knowledge, helps obtain necessary services, and can lead to more effective coping.

Though studies in SLE have used instruments that include all three of these types of support, they are often grouped together, and there has been less attention paid to the differential contributions of each type of support to health outcomes. Research has found that different types of support may be appraised differently and have different outcomes. For example, in a sample of cancer survivors, emotional support (such as comforting and reassuring) and providing problem-solving assistance (informational support) were associated with the ability of survivors to find positive meaning and have better psychological well-being, while tangible or instrumental help was not (Schroevers *et al.*, 2010).

2.2.2 Social Support and Health

Social support has been widely studied in healthy populations, as well as in those with a variety of health problems (Cobb, 1976; La Rocco & Jones, 1978; Lin *et al.*, 1979; House, 1981; Mitchel *et al.*, 1982; Williams *et al.*, 1985; House *et al.*, 1988; Dickens *et al.*, 2002; Ostir *et al.*, 2002; Gallant, 2003; Siegert & Abernethy, 2004; Moses *et al.*, 2005; Uchino, 2006; World Health Organization, 2008). Studies suggest that supportive social relations reduce the adverse consequences of a wide variety of stressful life events [see reviews by Cobb (1976), House (1981), Mitchell, Billings, & Moos (1982) and Uchino (2006)]. Much attention has been given to whether social support provides a main effect or a buffering effect on well-being. Studies find mixed results, with some research in chronic illness showing that social support contributes to greater psychological wellbeing irrespective of the level of life stress (i.e., a main effect of support) [e.g., LaRocco & Jones (La Rocco *et al.*, 1978); Lin, Simeone, Ensel, & Kuo (Lin *et al.*, 1979); Williams, Ware, & Donald (Williams *et al.*, 1985)], while other studies find that informal

support from others is most relevant at high levels of stress and can buffer or protect a person from the mentally or physically pathogenic effects of high stress (Cohen & Wills, 1985).

Support can help individuals redefine events as less stressful or moderate between the experience of stress and the onset of a negative health outcome by reducing the stress reaction or by directly influencing physiological processes (House, 1981). Support can provide instrumental help or solutions to problems or encouragement for behaviours that would reduce stress (House, 1981). What has not been fully elucidated is why, and under what circumstances social support is evaluated positively or negatively, and its relationship to well-being and disease appraisals. Because this thesis addresses support within the context of living with a stressful chronic condition, examination of whether a main effect or a stress buffering role of support exists for the sample will not be examined. Instead, this thesis aims to understand how support is appraised or evaluated, and its relationship with well-being.

2.2.3 Problematic Support

Using existing frameworks, social support is often studied from the perspective that greater support is expected to be associated with greater benefits to mental and physical well-being. However, theoretical discussions of support also highlight that support can be more complex. Though the literature in this area is small, a handful of authors have discussed negative support in terms of unpleasant interactions with others that attempt to deter some behaviours by shaming, criticizing or pressuring individuals (Stephens *et al.*, 1987; Israel *et al.*, 1989; Kessler & Aseltine Jr. *et al.*, 1990; Ray, 1992; Kelsey *et al.*, 1996). Support also may be unsolicited, unwanted, inadequate, or act as a barrier to self-

management, and may have adverse effects on psychological and functional outcomes (Sarason & Sarason, 1985; Lim *et al.*, 1988; Manne & Zautra, 1989; Rook, 1990; Revenson *et al.*, 1991; Riemsma *et al.*, 2000; Kozora *et al.*, 2005; Fekete *et al.*, 2007). Some research finds that even when providers feel they are being helpful, their assistance may be perceived as negative by the recipient (Cohen *et al.*, 1985). A study of 101 rheumatoid arthritis patients found that all respondents reported receiving some degree of unhelpful, unwanted, or inappropriate support from at least one member of their social circle (Revenson *et al.*, 1991). This raises the notion that support may be associated with greater well-being, not when it is maximized (increasing the overall quantity of support), but when the receipt of support is concordant with the individual's needs or desires for support.

The possibility that support is not always a positive stimulus may be particularly important given the complex nature of lupus. Different types of support (instrumental, emotional, and informational) may be needed at different times and in specific life domains (e.g., marital and family relationships, leisure activities) (Cohen *et al.*, 1985; Revenson *et al.*, 1991; Schroevers *et al.*, 2010; Linden & Vodermair, 2012). Moreover, requiring and receiving support may also be related to important aspects of an individual's identity, namely their perceptions of being able to manage their needs independently. There is a paucity of data examining social support needs in SLE and their relationship to perceived independence and dependence.

2.3 Independence and Dependence

2.3.1 What is meant by Independence and Dependence?

The concept of independence is often used to describe a situation where an individual is free from the control or influence of others. Conversely, an individual is considered dependent if they are in receipt of assistance or reliant on others to complete activities and tasks (Gignac *et al.*, 2000). However, it has been argued that independence and dependence are multi-dimensional and vary by domain, with most individuals being interdependent on others (providing support and receiving support; acting autonomously as well as being dependent on others) in many areas of their life (Kaufman, 1994; Cordingley & Webb, 1997; Gignac & Cott, 1998).

Feelings of independence are theorized as essential for psychological growth, integrity and well-being, and this is supported in the literature (Cott & Gignac, 1999; Ryan & Deci, 2002; Nagurney *et al.*, 2004; Neville *et al.*, 2005; Alpass *et al.*, 2007; Breitholtz *et al.*, 2013; Talley *et al.*, 2012). However, much of this literature has focused on older adults. We know little about perceptions of independence and dependence among women with SLE. They, too, may experience losses of independence, but their experiences and needs likely vary from those of older adults, owing to their stage of life and health characteristics and experiences.

2.3.2 Independence/Dependence and Social Support

Though independence and autonomy are often valued attributes, individuals may differ in their desires for independence or dependence. Additionally, others may misunderstand the amount or type of support an individual desires and when an individual wants support or not (Wortman & Dunkel-Schetter, 1979; LaRocco, House & French, 1980; Peters-Golden, 1982). Social support may not be well-received when there is a divergence between provision of support and desires to maintain independence (Reich & Zautra, 1991; Schiaffino & Revenson, 1995). In fact, those with greater desire for independence may experience less satisfaction with support from others (Nagurney *et al.*, 2004), even if they believe that they need that support. Additionally, the need for and provision of support may change one's perception of their independence. A study of older adults with chronic illness and disability found that when respondents perceived that their independence was being challenged they were more likely to report greater feelings of helplessness and poorer perceived coping efficacy (Gignac *et al.*, 2000).

Gignac and Cott (Gignac & Cott, 1998) provide a conceptual model of independence and dependence in the context of adults living with chronic physical illness. They note that individuals may perceive themselves to be independent, not independent, dependent, or perceive a situation of imposed dependence, depending on the support they perceive that they need and the actual support they receive. The present study adapts this model to examine independence in terms of support received and each individual's evaluation of the support received (in terms of amount of support). Different independence groups resulting from combinations of support received and evaluations of support, as well as how these groups are further grouped into concordant or discordant relationships, are presented in **Figure 1** and described below. Individuals described as *Independent* will be those who have little need for support and also receive little or no support. They are expected to appraise their situation as satisfactory. Individuals who perceive that they are receiving support and that this support is adequate to meet their needs are thought to be

Dependent on others. Though being independent and being dependent are seemingly very different states, and dependence can have negative connotations, by virtue of support needs and receipt of support being *concordant*, we hypothesize that a Dependent individual's appraisals of their support will also be satisfactory.

Individuals who perceive that they do not receive the amount of support they need to meet their support needs are *Under-Supported* if they receive some support, or *Not Independent* if they perceive no support received at all. They are not considered Dependent because they do not rely on others. They are not Independent either, because they perceive that they are unable to manage all of their roles or activities on their own. Finally, individuals may perceive *Imposed Dependence* when they receive support that they believe is unnecessary or in excess. Although support of any kind might seem to be beneficial, some research suggests that this is not always the case, and that these individuals may resent others or even display learned helplessness (Coyne *et al.*, 1980; Baltes *et al.*, 1983; Baltes, 1995). Relationships where individuals are Under-Supported, Not Independent or perceive Imposed Dependence are classified as *discordant* supportive relationships in this study because their support needs are in discordance with the support they do or do not receive.

It is important to note that these categories do not reflect a permanent state for an individual, but instead may differ across life domains or over time (Gignac *et al.*, 2000). Individuals may be independent in one life domain, but dependent in another. Further, independence may vary by support type (instrumental, emotional, or informational), and a discordant relationship may exist for one or more types, but not the others. Additionally, the concept of receiving the "right" amount of support is highly individual

and will vary from one person to another, which necessitates the assessment of each individual's perceptions and appraisals; it cannot be properly assessed by observation and comparison with others.



Figure 1. Independence groups and concordance/discordance

2.4 Psychological Perceptions and Well-Being in SLE

As noted earlier, many studies have described a positive association between social support and well-being in SLE (Karlson *et al.*, 1997; Dobkin *et al.*, 1999; Sutcliffe *et al.*, 1999; Alarcon *et al.*, 2001; Failla *et al.*, 2009; Zheng *et al.*, 2009), but have limited generalizability due to small sample sizes. The available literature in chronic disease as a whole suggests that there is a potential for dissatisfaction when support received does not

match support needed in terms of timing, type, setting, or amount. Linden and Vodermaier (2012) tested a match-mismatch model of support with cancer patients and healthy controls. Their findings supported the notion that distress is greatest in situations where desire and receipt of support were not congruent. Many studies have reported decreased well-being in SLE populations (McElhone *et al.*, 2006). However, the most commonly-used measures assess health-related quality of life (HRQoL), which may capture some disability and reliance on instrumental support, but do not fully account for psychological well-being. The links between support, independence and dependence, and a broader concept of well-being have not been examined, though SLE patients describe quality of life not only in terms of "feeling healthy, feeling good" but also in terms of "being independent" (Seawell & noff-Burg, 2004).

2.4.1 Depressive Symptomatology

Depressive symptomatology has been examined as a marker of psychological well-being. A review of the literature reveals that depression is prevalent in those with SLE, and there is evidence that it is associated with a number of clinical and psychosocial factors (Karol *et al.*, 2013; Palagini *et al.*, 2013). For example, depressive symptoms, more so than disease activity levels, have been associated with poorer quality of life in SLE patients (Moldovan *et al.*, 2011). However, findings for the relationship between depressive symptomatology and social support are mixed. In a number of studies, low support or interpersonal conflict with others is associated with a greater likelihood of having depression (Weissman & Paykel, 1974; Coyne, 1976; Brown & Harris, 1978; Veiel, 1987; Vilhjalmsson, 1993; Paykel, 1994; Frasure-Smith & Lesperance, 2000; Leserman, 2000; Vanderhorst & McLaren, 2005; Arthur, 2006; Ibarra-Rovillard & Kuiper, 2011). A

study of 101 women with osteoarthritis found that negative reactions to spousal support were related to greater depressive symptomatology (Martire *et al.*, 2002).

2.4.2 Life Satisfaction

Life satisfaction assesses global, cognitive appraisals of contentment with one's life and is used as a measure of subjective well-being (Pavot *et al.*, 1991; Pavot & Diener, 2008) or as a key component of well-being (Andrews & Withey, 1976). Life satisfaction has also been shown to be associated with other subjective measures of well-being (Pavot *et al.*, 1991). Research on life satisfaction in individuals living with SLE is lacking, but use in the general population and other chronic illnesses supports its use as an important outcome (Bowling & Browne, 1991; Bowung *et al.*, 1991; Wang *et al.*, 2002; Abu Bader *et al.*, 2003; Kahn *et al.*, 2003; Kafetsios & Sideridis, 2006; Phillips *et al.*, 2008; Strine *et al.*, 2009; van Leeuwen *et al.*, 2010).

Predictors of life satisfaction are diverse, and related to a range of demographic, health and other life factors (Brown *et al.*, 1981; Abu Bader *et al.*, 2003). Moreover, research finds that life satisfaction is related to perceived social support (Kazarian & McCabe, 1991; McColl *et al.*, 1999) and that positive views of support are related to increased life satisfaction (Martire *et al.*, 2002). Excessive support has been related to reduction in feelings of autonomy and independence as well as decreased life satisfaction (Silverstein & Bengston, 1994).

2.4.3 Illness Intrusiveness

Illness intrusiveness refers to appraisals of illness-induced disruptions or interference in life activities and roles (Devins & Binik, 1983). Illness intrusiveness is thought to be an

intervening variable between disease characteristics (such as mental and physical problems or limitations) and well-being in a range of diseases, including SLE (Devins et al., 2005). Intrusiveness intervenes by reducing participation in valued activities and adversely altering perceptions of personal control to achieve positive outcomes or avoid negative ones, both of which may increase emotional distress (Devins *et al.*, 1993; Devins *et al.*, 1994). That is, greater disease or symptom severity is associated with more perceived intrusiveness, which in turn, is related to greater psychological distress and poorer well-being. As such, illness intrusiveness is examined as an important psychological perception of the negative impacts of SLE on one's life. There is a substantial volume of evidence in the literature, some of which has focused on lupus, that illness intrusiveness is related to quality of life (Edworthy et al., 1998; Devins, Edworthy & Aramis, 2000; Devins et al., 2000; Kiani & Petri, 2010; Schattner et al., 2010; Nicassio, Carr & Moldovan, 2011). One particularly large study of 405 women with SLE found that higher illness intrusiveness was associated with decreased quality of life (Devins *et al.*, 2000). Finally, some authors speculate that illness intrusiveness may undermine or reduce perceptions of personal control (Devins, 1994), and personal control may be conceptually linked to independence. As a result, illness intrusiveness is included in this research as a factor related to well-being that may provide insight into understanding support and independence in women with lupus.

2.4.4 Meaning of Illness

The concept of meaning in illness refers to how individuals appraise themselves in relation to the world in the context of living with a chronic illness (Fife, 1994). The capacity to find positive meaning reflects the ability to find a sense of purpose and to

cognitively overcome personal struggles and limitations (Lewis, 1989; O'Connor *et al.*, 1990; Barkwell, 1991; Coward, 1991; Reed, 1991). Meaning of Illness (MOI) is not commonly used to describe well-being. However, it is relevant to include as a well-being measure in that these feelings and behaviours are thought to contribute to positive adjustment and emotional well-being (Fife, 1994). An individual's perceived meaning of their illness is also related to social support. Specifically, studies find that social support can buffer the negative associations and perceptions of an illness and related to better well-being (Downe-Wambolt *et al.*, 1996; Farber *et al.*, 2003; Ferrell *et al.*, 2003; Bussing *et al.*, 2005).

Perceptions of the meaning of illness have not been measured extensively in SLE. Yet, in one study, individuals with SLE often perceived their illness as severe and difficult to manage, regardless of their physicians' clinical perceptions (Daleboudt *et al.*, 2011). This highlights the importance of understanding cognitive appraisals and reactions to an illness in SLE.

2.5 Life Domains of Potential Difficulty

Research on disability has examined diverse activities, domains, and roles, such as personal care; education or employment; household activities; socializing, caregiving and other interpersonal relationships; and leisure activities. Although these areas of life are interconnected, they are often measured as discrete domains. Moreover individuals may be satisfied in one area of life while being dissatisfied or unhappy in others (Vennhoven, 1984). Some life domains may be of more importance, value, or relevance to an individual (Cummins, 1996). For example, some individuals may value leisure activities more than household activities. Which domains are important to an individual may

influence the amount and type of support they feel that they require, and their appraisals of independence and dependence. Gignac, Cott and Badley (2000) studied a population of older adults with osteoarthritis and osteoporosis and found that their perceptions of their independence, dependence, and psychological variables, like helplessness and coping efficacy, varied in relation to the domain of the activity examined.

This thesis focuses on five domains of life that have been identified previously as important to individuals in the quality of life literature, each with strong theoretical and empirical evidence (Cummins, 1996). These domains were also defined as important in a study of 50 women with SLE (Archenholtz *et al.*, 1998). They are: employment and education; family relationships; recreation and social activities; personal finances; and household maintenance. The following represents a summary of the literature examining the roles and potential limitations of a woman with a chronic illness in each domain, as well as the case for the importance of the domain.

2.5.1 Employment and Education

The most often-examined domain in SLE is employment. The burden of disease activity, particularly fatigue, in those with SLE was associated with work loss in a study of 511 American individuals with lupus (Drenkard *et al.*, 2014). Additionally, several studies have documented increased changes in work status, hours or job type, use of sick days, the need for work adaptations, and intrusiveness of SLE into work situations among many individuals living with lupus (Partridge *et al.*, 1997; Mau *et al.*, 2005; Bertoli *et al.*, 2007; Panopalis *et al.*, 2007; Yelin *et al.*, 2007; Al-Dhanani *et al.*, 2009; Baker *et al.*, 2009; Yelin *et al.*, 2009; Al-Dhanani *et al.*, 2015). Especially pertinent to this study is one finding of the LUpus in Minorities, Nature versus nurture (LUMINA)
study that poor social support may be associated with work disability (Bertoli *et al.*, 2007). Further, Jetha and co-authors (2014) report that greater perception of independence was associated with greater likelihood of employment, even after controlling for illness, demographic and work factors. Though this work could not elucidate the direction of the relationship, the presence of an association highlights the need to include this domain in a discussion of independence. Little research has examined participation in educational activities, though work and education are linked: lower education often leads to less stable and lower-paying employment, as well as increasing the risk of unemployment (Partridge *et al.*, 1997; Yelin *et al.*, 2007; Campbell *et al.*, 2009). Additionally, higher education is associated with more social support and life satisfaction in the general population (Mookherjee, 1992; Turner & Marino, 1994, Barrett, 1999).

2.5.2 Family Relationships

Family members are often the source of social support, but these relationships may also create a need for support. To date, there has not been a great deal of research on marital and other family relationships in SLE. In the general population, those who are married are less likely to report low life satisfaction than the never-married and those with dissolved partnerships (Gove *et al.*, 1983). One model of support as a coping mechanism in chronic illness postulates that a chronic illness and its resulting difficulties and stressors are shared between an individual and their spouse to produce, ideally, better outcomes (Berg & Upchurch, 2007). Participants in the qualitative component of one small study stated that family relationships were important to them, and that these relationships, as well as their participation in spousal and parental roles, was adversely

affected by SLE (Hasset *et al.*, 2012). It has also been suggested that strain in marital relationships may be exacerbated by the prevalence of sexual dysfunction related to SLE (Druley, Stephens & Coyne, 1997; Tristano, 2009). Parenting tasks, particularly those necessary for caring for small children, such as active play, carrying a child and, disrupting sleep to provide care were impacted by SLE symptoms (Poole *et al.*, 2012; Poole *et al.*, 2014). Studies of arthritis, chronic renal disease, and systemic autoimmune rheumatic diseases other than SLE find that many individuals report that balancing disease challenges, and the challenges raised by the disease in other life domains results in altered marital relationships and relationships with children, particularly related to not being able to perform activities with family or provide caregiving to the extent desired (Binik *et al.*, 1990; Grant, 2001; Gignac *et al.*, 2006; Backman *et al.*, 2007; Gignac *et al.*, 2013; Poole *et al.*, 2014).

2.5.3 Recreation and Social Activities

In healthy populations, participation in leisure activities is associated with quality of life (Binik *et al.*, 1990). Though discretionary activity may not seem to be a priority when faced with a serious illness, maintaining discretionary activities, particularly those involving physical activity, have been rated as highly important to individuals (Cott & Gignac, 1999; Hewlett *et al.*, 2001) and may be linked to a sense of identity, well-being, and independence in chronic illness (Katz & Yelin, 1995; Ditto *et al.*, 1996; Gignac & Cott, 1999; Gignac *et al.*, 2000; Katz & Yelin, 2001; Gignac *et al.*, 2006; Gignac *et al.*, 2008; Gignac *et al.*, 2012). Gignac, Cott and Badley (2000) studied a group of 286 osteoarthritis and osteoporosis patients and found that receiving help was

modestly related to perceptions of independence and dependence in valued activities like leisure, and was not related to perceptions of helplessness or lower coping efficacy. Disability in discretionary activities has been shown to be common in SLE (Katz *et al.*, 2008), and in one qualitative SLE study, limitations in leisure activities were mentioned by two-thirds of respondents as a concept relevant to functioning in daily life (Bauernfeind *et al.*, 2009). Further explorations of discretionary activities in lupus, particularly how they relate to social support, are limited. One reason for this is the nature of activities within this domain, as opportunities to provide assistance with participating in a hobby may be limited – no one can take your place in a recreational activity while you receive the benefits. There may, however, be a less direct way to provide assistance, such as providing transportation, assisting with coping with the loss of an activity, or providing information about accessible or alternative activities.

2.5.4 Personal Finances

Research finds that financial difficulties are associated with considerable psychological stress. In a study of 1100 older adults from the general population, those with one or more financial problems within the previous year reported more depressive symptoms than those without financial concerns, and this relationship was buffered by social support (Krause, 1997). Additionally, the ability to provide for oneself financially may be linked to perceptions of independence. Financial distress has not typically been included in studies of the impact of SLE. However, some qualitative research with people living with arthritis finds that participants note the importance of having financial resources to better manage their disease and its impact (Gignac *et al.*, 2012). Financial resources are also related to access to care in SLE (Waters *et al.*, 1996). Despite the availability of

government-provided medical insurance in Ontario, further financial investments may be required for prescription drug coverage, complementary and alternative therapies, and travel to and from service providers. In fact, there is evidence that lower income significantly reduces survival rates in lupus (Kasitanon *et al.*, 2000), and may have a similar impact on the quality of life and well-being of survivors.

2.5.5 Household Maintenance

Though women make up an increasing percentage of the paid workforce, a disease such as SLE, which predominantly affects women, nonetheless results in large reductions in non-labour market activities, such as housekeeping and childcare (Gordon & Clarke, 1999). The impact of SLE on household activities, perceptions of support and their meaning for independence and dependence have not been examined. However, we know that women with SLE report that the fatigue, pain and, musculoskeletal stiffness or deformity that can accompany the disease may make common household tasks more difficult (Robinson *et al.*, 2010). Of particular interest is one study of individuals with osteoarthritis which found that receiving help with household activities was one of the only domains that was not associated with greater perceived dependence or loss of independence (Gignac *et al.*, 2000). Whether this is true for those with lupus is unclear.

2.7 Summary of Theoretical Framework and Model

Figure 2 illustrates a proposed model of social support, independence, and well-being in women with SLE based on the literature. A variety of life domains that are important to women may be impacted by SLE. The extent of the impact will relate to diverse factors, including clinical and health factors like disease duration, disease activity, fatigue, pain,

and disease severity. Specifically, greater disease activity and more severe symptoms are expected to be associated with a greater negative impact in some or all domains. The impact of SLE on domains of life is also expected to relate to other factors, including demographic characteristics like age, marital status, education, annual household income, and work status. For example, employment and education may be less relevant or valued if the respondent is already retired. Lower education and less household income may be related to a greater impact or worry more about personal finance.

Social support may be drawn upon to help manage the impact of SLE on these diverse domains of life. The receipt of support will be influenced by social network characteristics, including the size and strength of social network associations and the availability of individuals who can offer support. That is, a person with strong ties to many close friends and family members who are available to offer support may be more likely to receive support if needed. An individual may appraise her receipt of support as satisfactory (a sufficient amount *for that individual*) or unsatisfactory (not enough or too much support *as appraised by that individual*). The combination of receiving or not receiving support and appraising the support as satisfactory or unsatisfactory is hypothesized to relate to perceptions of independence. In turn, an individual's appraisal of their independence is expected to relate to perceptions of well-being.

There is the potential for additional relationships among the concepts that are not shown (bi-directional relationships, etc.). However, modeling these potential pathways is beyond the scope of this study. The concepts shown in the model do not represent an exhaustive list, but act to illustrate the main concepts.



Proposed model of social support, independence and well-being in women with SLE Figure 2.

3.0 METHODOLOGY

3.1 Study Design, Recruitment and Data Collection

3.1.1 Study Design

A cross-sectional study design was used to achieve study objectives, and a survey was created that included measures with established validity and reliability, as well as questions developed specifically for this thesis.

3.1.2 Study Pool and Eligibility Criteria

A convenience sample was drawn from a cohort of Canadian women with SLE treated in a large tertiary rheumatology centre in Toronto, Ontario, Canada: The Centre for Prognosis Studies in Rheumatic Diseases (CPSRD) Lupus Clinic ("The Lupus Clinic"). The Lupus Clinic is a referral centre for patients from across Ontario and, occasionally, from other provinces. As a rare disease, SLE is most often treated in specialized clinics in Canada (Clarke *et al.*, 1999). As such, recruiting through the clinic made the study feasible and the results will likely have some generalizability to the broader SLE context. Potential participants were eligible for the study if they were:

- Female;
- 18 years of age or older;
- Diagnosed with SLE by a physician according to the American College of Rheumatology (ACR) SLE classification guidelines (Hochberg, 1997);
- Actively treated in the lupus clinic, having had a visit within the previous year;
- Able to understand and complete an English-language questionnaire; and
- Previously consented to be considered for participation in research studies.

In gauging the necessary sample size to perform analyses, accepted statistical heuristics were implemented. Specifically, a sample that included 15 observations (subjects) per parameter (variable) was deemed desirable, based on the *ad hoc* recommendations of 12-15 observations per parameter being estimated (Nunnally, 1967). Each objective was anticipated to need to include approximately 96 - 120 observations.

3.1.3 Recruitment Procedure

Potential participants were electronically screened for eligibility by applying eligibility criteria to a query of the CPSRD database. All eligible participants were invited to participate in the study to: 1) maximize the sample size and increase statistical power; 2) describe the cohort as accurately as possible; and 3) obtain results which have a better likelihood of generalizability to a larger Canadian context. Data were collected primarily using a web-based survey. Participants could complete the survey on paper if desired, and these responses were then entered into the web-based platform. Completion of the study questionnaire took an average of approximately 25 minutes.

Initial contact was made to potential respondents using a mail-out invitation letter (APPENDIX II). The letter provided information about the study and noted that the Lupus Clinic and its staff rheumatologists were supportive of the research and encouraged patients to get involved in the study if they chose to do so. A telephone number was provided to address any questions participants might have about the study. A telephone number for University Health Network Research Ethics Board (UHN REB) also was provided. This same letter was included at the beginning of the web- and paperbased questionnaires. After reading this information, participants were asked to click or check (depending on response method) that they had read the information about the study

and that they consented to participate. The letter included the survey website address and a randomly-generated code to enter at the beginning of the survey. The code allowed for tracking of respondents and allowed participants to leave and re-start the survey if they chose. The invitation also noted that participants could request a paper survey (**APPENDIX III**) if they chose to complete the survey in that manner.

Two to four weeks after the initial mailing, all non-respondents were sent a reminder letter (**APPENDIX IV**) encouraging them to participate, or to call study staff if they had further questions. This same reminder was sent to remaining non-responders an additional 2 to 4 weeks after the first reminder. Respondents who called the survey voicemail number had their calls returned within 48 hours. Most calls were to request a paper survey. Other questions included how to leave and re-start the survey, and occasional technical issues, all of which were related to individual computer or internet connection problems and were resolved. Those with invitations that were undeliverable (returned-to-sender) had their addresses corrected, where possible, using the UHN's electronic medical records. Invitations were re-sent to updated addresses. Participants were considered refused if they called to decline the study, if the paper survey was returned blank or if no response was received after the second reminder was sent.

3.1.4 Ethical Considerations in the Use of Human Subjects

Approval for this study was obtained from the UHN REB. Approval was also obtained from the University of Toronto Ethics Committee (both approvals available in **APPENDIX V**). One amendment to the approved protocol was made (also available in **APPENDIX V**). Specifically, permission was granted to access pooled CPSRD Lupus Clinic data to compare demographic and clinical characteristics between the clinic cohort

and the study sample. Participants were told that their contact information and data collected from the survey was confidential. Moreover, respondents were not asked to provide their name or any identifying information on the questionnaire. Potentially identifying information, such as IP address and location, were not collected by the survey website and were not available to study researchers or the survey company. Responses were tracked using a list that linked the unique study ID to the potential respondent's name, housed on secure UHN servers.

Potential respondents were informed that their participation in the study was completely voluntary and that, whether they chose to participate or not, there would be no impact on the care they received at the Lupus Clinic. Participants were able to refuse to answer any question on the questionnaire that they wished and were able to terminate the web survey at any point. Data from partially-completed web surveys were retained and, where possible, included in analyses, unless the respondent expressly requested that their data be excluded and destroyed.

3.1.5 Data Handling and Record-Keeping

Data were recorded directly by participants into either the web-based survey or paperbased survey. Information contained in paper surveys was entered into the online platform by study staff. Variable coding was built into the web-based survey such that all data was coded when entered. Data was downloaded from the web-based survey platform directly to SAS-compatible files and stored on secure UHN servers. Only the PI (SM) had access to the data. All records and documents pertaining to the study will be retained at the study site for at least seven years from the completion of the study, as is required by law for non-clinical trial studies. The data from the web platform were examined for

completeness and quality before analysis. A complete description of this process can be found in **section 3.3: Statistical Analysis**.

3.2 Variables

3.2.1 Variables to Describe Socio-demographic Characteristics

Age. Respondents were asked to report their age in years at the time of completing the questionnaire.

Education. Education was assessed using a multiple-choice question, with 1 = less than high school; 2 = high school; 3 = some college or university, but no degree completed; 4 = undergraduate university degree or college diploma; 5 = some graduate school or professional training; and 6 = graduate or professional degree.

Annual Household Income. Total annual household income from all sources was asked using a multiple-choice question with the following categories: 1 = less than \$30,000; 2 = \$30,000 - \$50,000; 3 = \$50,000 - \$70,000; 4 = \$70,000 - \$100,000; and 5 = more than \$100,000.

Marital Status. Marital status was asked using a multiple-choice question with the following options: 1 = single (never married); 2 = married or living as married (common-law); 3 = widowed; 4 = separated; and 5 = divorced.

Work Status. Current working status was assessed using a multiple-choice question with the following categories: 1 = working full-time work; 2 = working part-time work; 3 = on sick leave, leave of absence or short-term disability; 4 = on long-term disability; 5 = not working outside the home, but looking for work; 6 = not working and not looking for

work (including homemakers, caregivers, etc.); 7 = retired; and 8 = student. Participants were able to select more than one category if they applied (e.g. working and student).

3.2.2 Variables to Describe Self-Reported SLE-Related Clinical Characteristics

Disease Duration. Participants are asked for the year they were diagnosed with SLE by a physician.

Flares. Assessment of how many lupus flares (periods of increased severity of SLE symptoms) occurred in the preceding three months. This ordinal variable asks participants to choose the option that best fits their symptoms, with variables including 0 = no flare; 1 = mild flare; 2 = moderate flare; and 3 = severe flare. This question has not been validated, but has been used previously in SLE populations (Al-Dhanani *et al.*, 2014).

Disease Activity. Presence and activity of lupus-attributable symptoms in the preceding three months as assessed on a 10 cm visual analog scale (VAS), where the scale is anchored at 0 cm (not active) on the left and 10 cm (very active) on the right. This method is not validated, but it has been established that visual analog scales can have excellent metric characteristics, sensitivity and reproducibility (Grant *et al.*, 1999) and capture the wide range of possible responses.

Fatigue Severity. Severity of fatigue (extreme tiredness) in the preceding three months as assessed by the participant on a 10cm VAS, where the scale is anchored at 0 cm (no fatigue) on the left and 10cm (very fatigued) on the right.

Pain Severity. Severity of pain symptoms in the preceding three months as assessed by the participant on a 10 cm VAS, where the scale is anchored at 0 cm (no pain) on the left and 10 cm (the worst imaginable pain) on the right.

Symptom Severity since Diagnosis. Severity of SLE symptoms and SLE disease activity since diagnosis was measured on a 10 cm VAS, where the scale is anchored at 0 cm (very mild/not active) and 10 cm (very severe/very active) on the right.

3.2.3 Variables to Describe Social Networks

Social Network Size and Strength. The composition of participants' social networks was assessed using the Lubben Social Network Scale (LSNS) (Lubben, 1988), with no changes to the original published scale. The LSNS is a validated self-report 10-item scale measuring embedded support, perceived support, and the reciprocation of support. All 10 items are highly inter-correlated (Cronbach's alpha = 0.70) (Lubben & Gironda, 2004). The total scale is calculated by summing across all 10 items, and ranges from 0 to 50 (Lubben, 1988). Higher scores indicate more cohesive social networks and more available social support.

Availability of Social Support Resources. The Medical Outcomes Study (MOS) Social Support Survey (MOS-SS) is a brief (7-items), multidimensional, self-administered scale (Sherbourne & Steward, 1991) designed to assess availability of emotional, informational and tangible (instrumental) support, as well as positive social interactions. All of the items correlate highly, and the scale is reliable (Cronbach's alpha = 0.97) (Sherbourne & Stewart, 1991). Construct validity was described in a study wherein the MOS-SS was correlated with several validated mental and physical health measures in a sample of

more than 2000 participants (Sherbourne & Stewart, 1991). This measure was chosen over others because of its basis in a theoretical framework (Norbeck *et al.*, 1981; House *et al.*, 1982; Sarason *et al.*, 1983; Cohen & Syme, 1985; Cohen & Wills, 1985; Cohen *et al.*, 1985; House & Kahn, 1985; Bloom, 1990), its ability to be self-administered, its relative brevity, and its focus on perceptions of support, which is the focus of the present study. Respondents use a Likert-type scale to indicate how often they have certain kinds of support available to them, where 1 = none of the time; 2 = a little of the time; 3 = some of the time; 4 = most of the time; and 5 = all of the time. Possible scores range from 7 to 35, where higher scores indicate more support resources. There are no published reference values for what constitutes a good or adequate level of support.

3.2.4 Variables to Characterize Well-Being

Depressive Symptomatology. The 20-item Centre for Epidemiologic Studies Depression Scale (CESD) (Radloff, 1977) was used measure depressive symptomatology. The CESD has high internal consistency (0.80) and test-retest reliability (0.40) (Radloff, 1977) and has been shown to differentiate between SLE patients and healthy controls in 17 of the 20 questions (Petri, 1996), making it a valid measure for the purposes of this study, and allowing for comparison with reported norms. Participants answer how often in the past week they have experienced the feelings represented by the statements using 0 = rarely or none of the time, 1 = some or a little of the time, 2 = occasionally or a moderate amount of time, and 3 = most or all of the time. Scores range from 0 (no depressive symptoms) to 60 (highest level of depressive symptomatology). Example statements include "I felt sad" and "I had crying spells." A cutoff score of 16 or more was proposed by the original author (Radloff, 1977). Because symptoms of some physical diseases may yield false

positives with depression symptoms (e.g., my sleep was restless; I could not get "going"), a cutoff score of 23 has also been used and will be adopted in this study (Boyd *et al*, 1982; Zich *et al.*, 1990; Hunter *et al.*, 2003).

Life Satisfaction. The five-item Satisfaction with Life Scale (SWLS) (Diener *et al.*, 1985) measures the degree to which individuals feel content and fulfilled with their life. The scale has been shown to have good internal consistency (0.85 - 0.87) and reliability (0.82 - 0.84) (Radloff, 1977; Pavot *et al.*, 1991). Validity has been established by correlating the measure with other measures of well-being (Pavot *et al.*, 1991; Pavot & Diener, 1993; Sandvik *et al.*, 1993) and by assessing its potential to discriminate differences between groups with different life circumstances. For example, prisoners, homeless individuals, and sex workers all scored in the low end of the scale (Joy, 1990; Baker *et al.*, 2004; Biswas-Diener & Diener, 2006). Participants rate how much they agree or disagree with statements on a Likert-type scale ranging from 1 = strongly disagree to 7 = strongly agree. Scale scores range from 5 (extremely dissatisfied) to 35 (extremely satisfied). A score in the range of 5 to 14 reflects dissatisfaction with life; scores between 15 and 24 indicate average life satisfaction; and scores greater than 24 indicate high life satisfaction (Diener *et al.*, 1985).

Illness Intrusiveness. The Illness Intrusiveness Rating Scale (IIRS) (Devins *et al.*, 1983) has been validated previously in several samples, including lupus patients (Devins *et al.*, 2000; Devins *et al.*, 2001; Edsworthy *et al.*, 2003; Devins *et al.*, 2006; Devins 2010; Kiani & Petri, 2010; Schattner *et al.*, 2010), and has been shown to differentiate between SLE patients based on a variety of characteristics (Devins *et al.*, 2001; Edworthy *et al.*, 2003; Devins, 2010). Internal consistency assessment among lupus patients resulted in a

Cronbach's alpha of 0.94 (Devins *et al.*, 2001). The original scale consists of 13 items reflecting life domains relevant to quality of life including: health; diet; work; active recreation; passive recreation; financial situation; relationship with spouse; sex life; family relationships; other social relations; self-expression/self-improvement; religious expression; and community/civic involvement. The scale was modified for this study to expressly ask about the intrusiveness of lupus and its symptoms, and also to include the following additional items: "school/educational activities", "household tasks and chores" and "energy and vitality". A not applicable option ("N/A") is also included for items which may not apply to all respondents (e.g. spousal relationship). Ratings are on a 7-point scale ranging from 1 = not very much to 7 = very much. Total scores are an average of responses to applicable items, with scores ranging from 1 (minimum intrusiveness) to 7 (maximum intrusiveness). There are no published cut-off values to indicate high intrusiveness. A score ≥ 4 is used in the present study to indicated significant intrusiveness.

Meaning of Illness. The Meaning of Illness Scale (MOI) (Fife, 2013) is a 9-item scale designed to operationalize the concept of meaning in the context of a life-threatening illness. The scale is reliable, with a Cronbach's alpha of 0.81 (Fife, 2013). Items were developed using symbolic interactionist theory, as well as qualitative data from interviews with cancer patients (Fife, 1994). Construct validity has been described in research examining different stages of disease trajectory (Weisman & Worden, 1986) and in the MOI's relationship with diverse emotional response variables (Fife, 2013). In the present study the word "illness" was replaced with "lupus" to ensure that patients are attributing their feelings to lupus and not to other conditions. Responses for each

statement range from 1 = strongly disagree to 4 = strongly agree. Total MOI scores are obtained by reversing items 1, 3 and 8, and summing across all items. Scores range from 9 to 45, with higher scores reflecting more positive meaning attributed to living with lupus. There are no published reference values to indicate positive or negative meaning. The present study defines negative meaning as scores less than 1 standard deviation below the sample mean and positive meaning as scores greater than 1 standard deviation above the sample mean.

3.2.5 Variables to Define Independence Groups and Concordance/Discordance

A novel social support questionnaire was designed for this study to define support needed, support received, and evaluation of support received (or not). Three types of support (instrumental, emotional and informational) were assessed in five life domains: a) employment and education; b) family relationships; c) recreation and social activities, d) personal finances; and e) household maintenance. Participants were asked to respond "yes" or "no" to the following: "Do you need this type of support?"; and "Are you receiving this type of support (whether or not you need it)?". Participants were additionally asked to respond to the question: "Are you receiving the right amount of support (whether or not you need it)?", with the following possible answers: "I would like more support"; "I am receiving the right amount of support"; or "I would like less support".

3.3 Statistical Analysis

Statistical Analysis System (SAS) version 9.4 for Windows was used for all data cleaning and analysis. Raw data were examined for errors and outliers. Each outcome scale was

examined for floor and ceiling effects (individual scale item-level analysis available in **APPENDIX VI**). All scales had acceptable ranges and distributions of responses. The data were also examined for missing values. Respondents who had multiple missing values on a scale or who did not answer some questions were removed from analyses using those scales. In cases of a single or random missing values, scale items were imputed, as appropriate (scoring and imputation rules for individual scales can be found in **APPENDIX VII**). A final data set of complete and accurate data was used for subsequent analysis.

3.3.1 Analysis to Describe the Sample

Descriptive statistics (means, medians, standard deviations, percentages, and interquartile ranges) of demographic, clinical, social network, and well-being variables were used, as appropriate, to describe respondents. Since no data was available from individuals who declined to participate in the study, we were unable to compare respondents to non-respondents. However, some comparisons were made between the sample and the entire female Lupus Clinic population using variables available in both datasets. Student's t-tests or Wilcoxon Rank Sum tests were used for continuous variables (age and disease duration) and Chi-square tests were used to compare categorical data (level of education, marital status and work status).

3.3.2 Analysis to Address Study Objectives

Further analysis was performed to address each of the study objectives in order.

3.3.2.1 Creating and Describing Independence Groups (Objective 1)

Data on need and receipt of support were analyzed for each recipient to determine assignment to an independence group. However, in examining the responses, it became apparent that some participants had interpreted the "support needs" questions differently than was intended. Specifically, some participants answered that they did not need support, but subsequently responded that they valued support they had received. For this reason, it was decided to focus not on perceived need, but instead to examine receipt of support and evaluation of that support to determine independence groups and concordance/discordance (**Figure 3**). This change introduced a fifth possible independence group – "Under Supported", which reflected those who were receiving support but appraised it as insufficient. Distributions of individuals into each group by domain and support type were examined. The number of discordant support relationships per individual was calculated to describe the support imbalance in the sample. Finally, the number of domains in which an individual had discordance was determined for each type of support.



Figure 3. Creation of independence groups

3.3.2.2 Independence Groups/Discordance and Well-Being (Objective 2)

Wilcoxon-Mann-Whitney tests of differences in mean well-being and disease appraisal outcomes between the Not Independent and Under-Supported groups in each domain and for each support type were performed. The Wilcoxon-Mann-Whitney test is a non-parametric analog to the independent samples t-test, and is used when it is assumed that the dependent variable is not normally distributed. There were no differences found, and these two groups were combined into one to increase cell size for subsequent analysis. The Imposed Dependence group was not included in this or subsequent analysis because of small-sized and empty cells. Analysis continued with three independence groups: 1) Independent; 2) Dependent; and 3) Not Independent/Under-Supported.

Separate *pre hoc* Wilcoxon-Mann-Whitney exact tests were performed for the well-being outcomes with the three independence groups in each domain and for each support type. There was evidence that the group means differed for all domains and support types, so analyses proceeded. The second step was to test for differences in each outcome mean among all combinations of the three groups (Independent vs Dependent; Independent vs Not-Independent/Under-Supported; Dependent vs Not Independent/Under-Supported) using *post hoc* Tukey multiple comparison tests.

Second, well-being and appraisal measure scores were plotted, examining the number of discordant domains for each individual, with separate analysis for each support type. Means, medians and confidence intervals for each well-being and appraisal outcome measure were plotted against the number of discordant domains on the same graphs. Wilcoxon-Mann-Whitney exact tests were used to determine any significant differences in well-being scale score by number of discordant domains.

3.3.2.3 Demographic, Clinical, and Social Network Characteristics Related to Independence Group (Objective 3)

Analyses continued with multinomial logistic regression, as suggested in the literature when the dependent variable (independence group) has more than two levels (Allison, 1999; Hosmer & Lemeshow, 2000). The purpose of these analyses was to examine associations of demographic, clinical, and social network variables with the independence groups. Separate analysis was performed for each domain and support type, and three independence types were again used for this analysis: 1) Independent; 2) Dependent; and 3) Not Independent/Under-Supported.

Selecting Variables for Multivariate Analysis

All of the demographic, clinical, and social network variables used in the study were chosen for their theoretical relevance, and as such all variables were included in the regression analyses. First, all variables were examined for collinearity using Spearman rank sum correlations (**APPENDIX VIII**). An r²-value of \pm 0.8 was used as a cut-off to determine if two variables were collinear, as suggested (Katz, 2006). None of the variables were collinear by this definition, though some pairs had r²-values > 0.6 or < - 0.6, suggesting moderate associations, and these were noted before beginning the model-building.

Categorical variables were converted to binomial categories as follows: marital status – married vs unmarried; education – less than high school vs high school or higher; annual household income – less than \$70,000 per year vs greater than or equal to \$70,000 per year; work status – involuntarily out of work (on disability, unemployed and looking for work) vs working (full-time or part-time) or voluntarily out of work (student, retired, not looking for work for other reasons); flares – no flare in the past 3 months vs any flare (mild, moderate, or severe) in the past 3 months); current activity – currently in remission vs any current activity (mild, moderate or severe). The continuous or ordinal variables (age, disease duration, lupus activity in the past 3 months, pain, fatigue, symptom severity since diagnosis, MOS-Social Support Scale scores, and Lubben Social Network Scale scores) were used as continuous predictors.

Model-Building Strategy

A multinomial logistic model was created with independence group as the dependent variable (using Independent as the reference group) and all of the demographic, clinical and social network variables as predictors for each domain and for each type of support within that domain. A screen of variables with bivariate analysis was not used for inclusion in the models, as there were theoretical reasons for including all of the variables. Additionally, studies have found that non-significant factors in bivariate analysis may be significant in multivariate analysis (Sun *et al.*, 1996). Including all variables ensured that potentially important variables were not rejected.

Manual backward elimination methods were used to create the final models for each domain and support type. First, a multinomial logistic model was created using all variables. Variables significant with p-values > 0.2 on the Wald test were removed at each step until all remaining variables were associated with independence group at p < 0.2. Wald statistics and associated p-values for overall association with independence group at p < 0.2. Wald statistics and associated p-values for overall associated 95% confidence group were produced for each variable. Odds ratios and associated 95% confidence intervals belonging for to the Independent group were also produced. The variables noted before model-building because they had r² values that suggested a moderately high degree of association (r²-values around 0.6 or -0.6) were not relevant to the final models and their inclusion in the final models did not need to be reconsidered.

4.0 **RESULTS**

4.1 Study Response and Description of Respondents

4.1.1 Overall Study Response

A total of 1781 patients are recorded in the CPSRD database and 699 met the inclusion criteria for this study. **Figure 4** illustrates the numbers of potential participants screened, who were excluded, who refused, and who responded to the survey.

Nearly 100 survey invitations were confirmed to be undeliverable and returned-to-sender (n = 97). Of these, only 29 addresses could not be updated or corrected using the UHN electronic medical record; the remaining were re-sent. Ninety-eight (98) survey responses were completed using the web-based questionnaire and 65 questionnaires were completed on paper, giving a total n of 163 responses and a response rate of 23.3%.



Figure 4. Study population

4.1.2 Survey Completion

Among responders, survey completion rates were high. The response rates for each section of the survey ranged from 78.5% to 100%, with most sections having completion rates around 90 - 95%. **Table 1** provides details of the response rate for each section.

	Section/Scale	# Responded to scale or section/ # Expected	# Items in Section/Scale	Section Response Rate (%)*
1.	Lupus Flares and Activity	162/163	7	98.1%
2.	Illness Intrusiveness Rating Scale (IIRS)	160/163	16	96.8%
3.	Prioritizing of Life Domains	128/163	1	78.5%
4.	Support Need, Receipt and Evaluation	148/163	15	86.3%
5.	Perceived Absence of Support Scale (PASS)	157/163	13	95.6%
6.	Lubben Social Network Scale	157/163	10	95.3%
7.	Medical Outcomes Study (MOS) Social Support Scale	134/163	7	82.2%
8.	Center for Epidemiologic Studies in Depression (CESD) Scale	154/163	20	94.0%
9.	Constructed Meaning of Illness (MOI) Scale	146/163	9	89.6%
10	Satisfaction with Life Scale (SWLS)	153/163	5	93.4%
11	. Demographic Information	163/163	5	100.0%

Table 1.Item response for each survey section, n = 163

* Item Response Rate = Total Items Answered by all respondents/ # Expected X Items in Scale

4.1.3 Comparing Respondents to the CPSRD Female Lupus Population

To examine responders and non-responders in the study, study participants were compared to the female population of the CPSRD Lupus Clinic in terms of the demographic and clinical variables that overlapped between the two datasets (**Table 2**). The study sample was older (about 51 years vs 48 years, p < 0.0001), and accordingly, had a longer disease duration (about 22 years vs 18 years, p < 0.0001) than the CPSRD population. The study sample was more highly educated (15% less than high school vs 30.3%, p = 0.0001) and more likely to be married (63.5% vs 52.4%, p < 0.0001). The study sample included fewer students than the CPSRD database (3.3% vs 8.3%, p = 0.0004).

Variable	Study Sample n = 163	Lupus Clinic Female Population n = 699	p-value
Age years			
Mean ± SD	50.7 ± 16.1	48.2 ± 16.5	< 0.0001
Disease Duration			
Mean ± SD	21.9 ± 13.7	18.3 ± 13.8	0.0035
Education			
\leq High School	23 (15.0%)	189 (30.7%)	0.0001
University/college	130 (85.0%)	426 (69.3%)	0.0001
Marital Status n (%)			
Single	23 (23.1%)	220 (35.3%)	
Married/Common-law	99 (63.5%)	327 (52.4%)	< 0.0001
Widowed	8 (5.1%)	19 (3.0%)	< 0.0001
Divorced/Separated	11 (8.4%)	58 (9.3%)	
Work Status n (%)			
Employed	67 (45.6%)	257 (48.8%)	
Retired	37 (25.2%)	62 (11.8%)	
Student	5 (3.4%)	52 (9.9%)	0.0004
On Disability	33 (22.4%)	138 (26.2%)	
Looking for Work	5 (3.4%)	18 (3.4%)	

Table 2. Study respondents compared to the Lupus Clinic female population

Notes: SD = standard deviation;

Number of responders (n) varies slightly for each variable; Percentages may not add to 100% because of rounding

4.1.4 Description of Respondents

4.1.4.1 Demographic Characteristics

Table 3 describes the demographic characteristics of survey responders (n = 163). The mean age of the sample was approximately 51 years, ranging from 19 years to 88 years. The majority of the sample was married (64.3%) and had completed a college diploma or university degree (40.5%), some graduate-level training (10.5%), or a graduate-level degree or diploma (18.3%). Annual household incomes were diverse: 20.3% made less than \$30,000 per year, 25.4% made more than \$100,000, and the remainder of the sample fell in between. A third of the sample was working full time (33.1%), 10.4% worked part-time, and 3.3% were students. Approximately a quarter of respondents (24.0%) were retired, 3.3% were unemployed and looking for work, 4.6% were not looking for work, and 21.4% were on either short-term or long-term disability.

Variables	Mean ± SD or n (%)	Range of Sample Responses
Age years, mean ± SD	50.7 ± 16.1	19.0 - 88.0
Marital Status		
Single/Never Married	36 (23.3%)	
Married/Living as Married	99 (64.2%)	
Separated/Divorced	11 (7.1%)	
Widowed	8 (5.2%)	
Education		
< High School	6 (3.9%)	
High School	17 (11.1%)	
Some College/University	24 (15.7%)	
Undergrad Diploma/Degree	62 (40.5%)	
Some Grad. School/Training	16 (10.5%)	
Graduate Degree/Diploma	28 (18.3%)	
Annual Household Income		
< \$30,000	28 (20.3%)	
\$30,000 - \$50,000	27 (19.6%)	
\$50,000 - \$70,000	15 (10.9%)	
\$70,000 - \$100,000	33 (23.9%)	
> \$100,000	35 (25.4%)	
Work Status n (%)		
Working Full Time	51 (33.1%)	
Working Part Time	16 (10.4%)	
Disability	33 (21.4%)	
Unemployed	5 (3.3%)	
Not looking for work	7 (4.6%)	
Retired	37 (24.0%)	
Student	5 (3.3%)	

Table 3. **Demographic characteristics of the sample**, n = 163

number of responders (n) varies slightly for each variable; percentages may not add to 100% because of rounding.

4.1.4.2 Self-Reported SLE-Related Clinical Characteristics

Self-reported SLE-related clinical characteristics of responders (n = 162) are presented in **Table 4**. The mean disease duration of the sample was approximately 22 years, with time since diagnosis ranging from 1 year to 61 years in duration. The majority of responders had no disease activity (50.3%) or mild disease activity (39.1%) at the time of survey completion; 66.7% and 22.8% reported no flares or only a mild flare in the preceding three months. Visual analog scale (VAS) ratings of disease activity in the past three months averaged 2.4 out of 10. However, ratings for fatigue and pain were higher, at 4.7 and 3.7 out of 10, respectively, and respondents rated their symptom severity since diagnosis an average of 5.3 out of 10.

Table 4.Self-reported SLE-related Clinical characteristics of the sample,
n = 162

Continuous Variables	Mean ± SD or n (%)	Range of Sample Responses
Disease Duration years, mean ± SD	21.9 ± 13.7	1.0 - 61.0
Symptom Severity Since Diagnosis 10pt VAS	5.3 ± 3.1	0.0 - 10.0
Disease Activity past 3 Months 10pt VAS	2.4 ± 2.6	0.0 - 10.0
Fatigue past 3 Months 10pt VAS	4.7 ± 3.7	0.0 - 10.0
Pain past 3 Months 10pt VAS	3.7 ± 3.1	0.0 - 10.0
Current Disease Activity n (%)		
in remission/no activity	81 (50.3)	
mild activity	63 (39.1)	
moderate activity	13 (8.1)	
very active	4 (2.5)	
Flare past 3 Months		
n (%)	100 (66 7)	
no flare	108 (66.7)	
mild flare	57 (22.8) 12 (8.0)	
moderate flare	13(8.0)	
severe flare	4 (2.3)	

Notes: SD = standard deviation

number of responders (n) varies slightly for each variable; percentages may not add to 100% because of rounding

4.1.4.3 Social Support and Social Network Characteristics

Respondent data from the social support (n = 134) and social network (n = 157) scales are presented in **Table 5**. The mean Medical Outcome Study Social Support Scale (MOS-SS) score was relatively high at 21 out of a possible 36, and subscales were similarly high. The mean Lubben Social Network Scale (LSNS) for the sample reflected good support (mean 32, sample range 0 to 36 of a possible 50). However, social isolation (a LSNS score of less than 20) was reported in 16.6% of the group. Given these scores, participants in the study generally had high levels of available social support and most were not socially isolated, though the proportion of the sample with low available support and considered to be in social isolation is noteworthy.

Variable	Mean ± SD	Range of Sample Responses
MOS Social Support Scale (MOS-SS) Scale Range: 0 – 36		
Total Scale Emotional/Affection Support Informational Support Instrumental Support	$\begin{array}{c} 21.04 \pm 6.29 \\ 12.46 \pm 3.79 \\ 5.75 \pm 1.96 \\ 2.78 \pm 1.21 \end{array}$	0 - 36 0 - 20 0 - 10 0 - 5
Lubben Social Network Scale (LSNS) Scale Range: 0 – 50 n = 157		
Total Scale % socially isolated Family Subscale Friends Subscale	$\begin{array}{c} 31.81 \pm 8.86 \\ 16.6\% \\ 9.46 \pm 3.65 \\ 6.49 \pm 2.73 \end{array}$	0 - 36 0 - 10 0 - 10

Table 5.	Social support and social network characteristics of th	e sample
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Note: SD = standard deviation

4.1.4.4 Well-Being and Appraisal Outcome Scales

Mean scale and subscale scores for the four well-being outcomes (depressive symptomatology (n = 154), life satisfaction (n = 153), illness intrusiveness (n = 160), and meaning of illness (n = 152) are presented in **Table 6**. The mean Center for Epidemiologic Studies Depression Scale (CESD) score was 15.3, ranging from 0 to 45 of a possible 60 points. A number of individuals were at or above the proposed cut-off values of 16 and 23 represented 42.1% and 25.0% of the sample, respectively. The mean Satisfaction with Life Scale (SWLS) score among respondents was relatively high at 23, ranging from 5 to 35 of a possible 35. Those with very high, average, and low satisfaction represented 48%, 32% and 20% of the group, respectively. The mean Illness Intrusiveness Ratings Scale (IIRS) score was 2.58, with individual scores ranging from 0.9 to 5.7 of a possible 7. Those with scores above 4.0 represented 20.6% of respondents. The mean Constructed Meaning of Illness (MOI) scale score for respondents was 23, ranging from 13 to 36 of a possible 45 points. Those with low meaning scores (scores less than 1 standard deviation below the sample mean) represented just 2.0% of respondents; those with high meaning scores (scores greater than 1 standard deviation above the sample mean) represented 13.4% of the sample. These data suggest generally high wellbeing for much of the sample, although a minority of participants reported poorer wellbeing.
Variable	Mean ± SD or % of sample	Range of Sample Responses
Center for Epidemiologic Studies Depression (CESD) Scale Scale Range: 0 - 60 n = 154		
Total Scale $\% \ge 16$ $\% \ge 23$	15.32 ± 10.90 42.1% 25.0%	0-45
Somatic/Depressed Affect Positive Affect	7.89 ± 5.60 8.73 ± 2.41	0 - 23 2 - 12
Interpersonal/Depressed Affect	4.16 ± 4.1	0-16
Satisfaction with Life Scale (SWLS) Scale range: 0 - 35 n = 153		
Total Scale % very high % average	$\begin{array}{c} 22.92 \pm 7.47 \\ 48.0\% \\ 32.2\% \end{array}$	5 - 35
% low satisfaction/dissatisfied	19.7%	
Illness Intrusiveness Rating Scale (IIRS) Scale Range: 0 - 7 n - 160		
Total Score $\% \ge 4$	2.58 ± 1.41 20.6%	0.91 - 5.73
Physical Well-Being & Diet Work & Finances	$\begin{array}{c} 2.66 \pm 1.67 \\ 2.00 \pm 1.60 \end{array}$	1.00 - 6.67 0.50 - 7.00
Marital, Sexual & Family Relations Recreation & Social Relations Other Aspects of Life	1.51 ± 1.41 2.48 ± 1.43 2.89 ± 1.63	0.50 - 6.00 1.00 - 6.67 1.00 - 6.67
Constructed Meaning of Illness (MOI) Scale		
Scale Range: 9 - 36 n = 146		
Total Scale Low positive meaning (≤ 1 SD below mean) % low positive meaning	23.3 ± 5.0 18.2 17.9.0%	13 – 36
High positive meaning (> 1 SD above mean) % high positive meaning	28.2 16.6%	

Table 6.Well-being and appraisal outcome scales

Note: SD = standard deviation

4.2 Results Related to Specific Study Objectives

4.2.1 Independence Groups and Concordance/Discordance

This section describes analyses for Objective 1, where the sample was examined in terms of different independence groups, and the concordance and discordance in support relationships examined among sample participants.

4.2.1.1 Independence Groups

The distributions of respondents in the five independence groups for each of the five domains and three support types is found in **Table 7**.

In the employment and education domain, many individuals were Independent in terms of instrumental and informational support (43.0% and 30.4%, respectively), while nearly half of respondents reported being Dependent in emotional support (52.3%). Informational support had the greatest proportion of individuals who were either Not Independent (31.2%) or Under-Supported (10.4%) in this domain.

The family relationships domain was characterized by dependence, with similarly high proportions of Dependent individuals for all three types of support (instrumental: 50.7% emotional: 49.6%, informational: 42.7%). Few individuals considered themselves Not Independent (15.3%) or Under-Supported (3.1%) in this domain.

The recreation and social activities domain followed a similar pattern, with Dependent being the predominant group for instrumental (40.0%) and emotional support (45.9%). Nearly a third of respondents reported being Dependent for informational support (30.7%).

Over half the sample considered themselves Independent for instrumental support in the personal finances domain (53.4%). Proportions of Independent and Dependent individuals were similar for the other two types of support.

In the household maintenance domain, 43.9% and 44.1% of individuals were Dependent for instrumental and emotional support, respectively, and nearly 40% were Independent for informational support (39.6%). About 1 in 5 participants reported being Not Independent (21.6%) and 10.8% Under-Supported for instrumental support.

The Independent and Dependent groups were consistently the largest groups across all domains and support types, however the actual distribution of respondents among all five groups varied widely. In most cases there were no individuals who considered themselves in a position of imposed dependence where they reported receiving unwanted support.

		Indeper	ndence Group n (1	row %)	
Domain	Concor	dant		Discordant	
Support Type	Independent	Dependent	Not Independent	Under- Supported	Imposed Dependence
Employment & Education					
Instrumental	55 (43.0%)	39 (30.5%)	29 (22.7%)	5 (3.9%)	0 (0.0%)
Emotional	21 (16.4%)	67 (52.3%)	24 (18.8%)	16 (12.5%)	0 (0.0%)
Informational	38 (30.4%)	34 (27.2%)	39 (31.2%)	13 (10.4%)	1 (0.8%)
Family Relationships					
Instrumental	51 (37.5%)	69 (50.7%)	12 (8.8%)	4 (2.9%)	0 (0.0%)
Emotional	26 (19.3%)	67 (49.6%)	30 (22.2%)	12 (8.9%)	0 (0.0%)
Informational	51 (38.9%)	56 (42.7%)	20 (15.3%)	4 (3.1%)	0 (0.0%)
Recreation & Social Activities					
Instrumental	51 (37.8%)	54 (40.0%)	24 (17.8%)	6 (4.4%)	0 (0.0%)
Emotional	29 (21.8%)	61 (45.9%)	32 (24.1%)	11 (8.3%)	0 (0.0%)
Informational	46 (36.2%)	39 (30.7%)	34 (24.8%)	7 (5.5%)	1 (0.8%)
Personal Finances					
Instrumental	70 (53.4%)	46 (35.1%)	12 (17.1%)	3 (2.3%)	0 (0.0%)
Emotional	47 (35.9%)	55 (42.0%)	24 (18.3%)	5 (3.8%)	0 (0.0%)
Informational	47 (36.7%)	39 (30.5%)	36 (28.1%)	6 (4.7%)	0 (0.0%)
Household					
Maintenance					
Instrumental	33 (23.7%)	61 (43.9%)	30 (21.6%)	15 (10.8%)	0 (0.0%)
Emotional	39 (28.7%)	60 (44.1%)	24 (17.6%)	13 (9.6%)	0 (0.0%)
Informational	53 (39.6%)	38 (28.4%)	38 (28.4%)	4 (3.0%)	0 (0.0%)

Table 7.Independence grouping by domain and support type, n = 139

Note: sample sizes vary slightly by row;

percentages may not add to 100% due to rounding

4.2.1.2 Concordance and Discordance

As described, the independence groups were subsequently consolidated into either concordant (Independent and Dependent subgroups) or discordant (Not Independent and Under-Supported subgroups) groups for each domain and support type. The Imposed Dependence group was removed from analyses because so few, if any, respondents reported this category across the domains. Distributions of concordant and discordant support relationships in each domain and for each support type are described in **Table 8**. In all domains and for all support types, the concordant group was larger than the discordant group.

Concordant relationships were predominant in all five domains for all three support types, though discordant relationships were not rare and represented up to one-third of the sample in several domains and types of support (range 11.8% - 42.4%).

Domain	Concordant	Discordant
Support Type	n (row %)	n (row %)
Education & Employment		
Instrumental	94 (73.4%)	34 (26.6%)
Emotional	88 (68.8%)	40 (31.3%)
Informational	72 (57.6%)	53 (42.4%)
Family Relationships		
Instrumental	120 (88.2%)	16 (11.8%)
Emotional	93 (68.9%)	42 (31.1%)
Informational	107 (81.7%)	24 (18.3%)
Recreation & Social Activities		
Instrumental	105 (77.8%)	30 (22.2%)
Emotional	90 (67.7%)	43 (32.3%)
Informational	85 (67.5%)	41 (32.5%)
Personal Finances		
Instrumental	116 (88.5%)	15 (11.5%)
Emotional	102 (77.9%)	29 (22.1%)
Informational	86 (67.2%)	42 (32.8%)
Household Maintenance		
Instrumental	94 (67.6%)	45 (32.4%)
Emotional	99 (72.8%)	37 (27.2%)
Informational	91 (68.4%)	42 (31.6%)

Table 8.Concordance and discordance, by domain and support type,
n = 139

Note: sample sizes vary slightly by row;

percentages may not add to 100% due to rounding

As described, participants were then grouped by the number of domains in which they experienced a discordant support relationship for instrumental (n = 121), emotional (n = 116), and informational support (n = 115). Distributions of respondents among these groups are presented in **Table 9** and **Figure 4**.

For all three support types (instrumental, emotional, and informational), about half the sample did not experience discordance in any of the five domains (47.7%, 53.9% and 42.7%, respectively). However, that left half the sample experiencing discordance in at least one domain. Only a small proportion of the sample experienced discordance in all five domains, and was more common for emotional support (13.5%) than instrumental (1.9%) or informational support (8.7%).

# Discordant		Support Type	
# Discordant Domains	Instrumental , n (%)	Emotional , n (%)	Informational , n (%)
0	51 (47.7%)	56 (53.9%)	44 (42.7%)
1	24 (22.4%)	7 (6.7%)	12 (11.7%)
2	14 (13.1%)	10 (9.6%)	12 (11.7%)
3	7 (6.5%)	5 (4.8%)	9 (8.7%)
4	9 (8.4%)	12 (11.5%)	17 (16.5%)
5	2 (1.9%)	14 (13.5%)	9 (8.7%)

Table 9.Distribution of number of discordant domains, by support type,
n = 107

Notes: percentages may ot add to 100% because of rounding





4.2.2 Independence Groups, Domains of Discordance, and Well-Being and Health Appraisals

The following two sections present analyses for Objective 2, which examines the associations between independence groups and concordance/discordance and the four well-being outcomes.

4.2.2.1 Independence Groups and Well-Being and Appraisal Outcomes

Comparison of mean well-being outcome scores between independence groups in the employment and education, family relationships and recreation and social activities domains are presented here. Data for finances and household activities can be found in

APPENDIX IX.

Analyses of Variance (ANOVA) examined significant differences in mean well-being scores across all three independence groups and *post hoc* Tukey tests examined differences between each pair of independence groups. No significant differences were found between the Not Independent and Under-Supported groups, and as such, they were combined for subsequent analyses. **Tables 10, 11** and **12** compare the mean well-being scores between groups for each support type in the employment and education, family relationships, and recreation and social activities domains, respectively. With few exceptions, the Independent group had greater well-being scores than the Dependent group, although these differences were mostly not significant, and both the Independent and Dependent groups had significantly greater well-being scores than the Not Independent group.

	Iı	ndependence Gro (outcome mean ± S	Dup D)	Between	Group Com	parison [‡]
Outcome Type of Support	Conco	ordant	Discordant			L
	Independent	Dependent	Not Independent/ Under-Supported	IN vs DE	IN vs US	DE vs US
CESD						
[†] Instrumental	13.94 ± 11.30	14.87 ± 11.12	21.06 ± 9.62	NS	***	***
[†] Emotional	8.95 ± 7.17	14.08 ± 10.88	23.00 ± 10.40	NS	***	***
[†] Informational	11.08 ± 9.09	14.00 ± 11.22	21.59 ± 10.79	NS	***	***
SWLS						
[†] Instrumental	24.52 ± 7.78	23.84 ± 6.47	$21.06\pm9.62b$	NS	***	***
[†] Emotional	25.50 ± 7.63	24.63 ± 6.97	18.68 ± 6.14	NS	***	***
[†] Informational	25.32 ± 7.38	23.03 ± 8.08	21.06 ± 6.87	NS	***	NS
IIRS						
[†] Instrumental	2.07 ± 1.25	2.79 ± 1.48	$3.51 \pm 1.36b$	NS	***	***
[†] Emotional	1.85 ± 1.34	2.62 ± 1.39	3.11 ± 1.52	NS	***	***
[†] Informational	1.90 ± 1.18	2.65 ± 1.40	3.23 ± 1.44	NS	***	NS
MOI						
[†] Instrumental	24.59 ± 5.11	22.79 ± 4.21	20.56 ± 4.19	***	***	NS
[†] Emotional	25.65 ± 6.56	25.55 ± 4.14	20.37 ± 3.60	NS	***	***
Informational	25.00 ± 5.28	23.27 ± 4.78	21.16 ± 3.96	NS	***	NS

Table 10.Outcome scores by independence group and support type, Employment
and Education domain, n = 124

Notes: SD = standard deviation

 \dagger pre hoc F-test across all three groups significant at p < 0.05

 \ddagger IN – Independent; DE – Dependent; US – Not Independent/Under-Supported

*** Difference in means significant at p < 0.05

	Ι	ndependence Grou (outcome mean ± SD)	p	Between	Group Comp	arisons [‡]
Type of Support	Conco	ordant	Discordant		1 1	
	Independent	Dependent	Not Independent/ Under-Supported	IN vs DE	IN vs US	DE vs US
CESD						
[†] Instrumental	14.18 ± 10.47	14.35 ± 10.63	28.07 ± 9.11	NS	***	***
[†] Emotional	11.08 ± 10.19	11.82 ± 8.43	25.39 ± 10.03	NS	***	***
[†] Informational	13.04 ± 9.30	14.67 ± 11.00	24.00 ± 11.22	NS	***	***
SWLS						
[†] Instrumental	23.91 ± 7.40	23.79 ± 6.63	15.13 ± 5.30	NS	***	***
[†] Emotional	24.64 ± 8.31	25.30 ± 5.88	17.59 ± 6.38	NS	***	***
[†] Informational	24.39 ± 6.88	23.26 ± 7.27	18.43 ± 6.59	NS	***	***
IIRS						
[†] Instrumental	1.98 ± 1.06	2.83 ± 1.42	3.91 ± 1.39	***	***	***
[†] Emotional	1.99 ± 1.16	2.44 ± 1.28	3.40 ± 1.47	NS	***	***
[†] Informational	2.08 ± 1.78	2.74 ± 1.37	3.55 ± 1.59	***	***	***
MOI						
[†] Instrumental	23.51 ± 4.76	23.46 ± 4.49	17.93 ± 2.84	NS	***	***
[†] Emotional	23.95 ± 5.75	24.34 ± 4.06	19.85 ± 3.91	NS	***	***
[†] Informational	23.88 ± 5.25	23.35 ± 4.42	20.26 ± 3.45	NS	***	NS

Table 11.Outcome scores by independence group and support type, Family
Relationships domain, n = 133

Notes: SD = standard deviation

 \dagger pre hoc F-test across all three groups significant at p < 0.05

 \ddagger IN – Independent; DE – Dependent; US – Not Independent/Under-Supported

*** Difference in means significant at p < 0.05

NS

NS

NS

NS

	Iı	ndependence Grou (outcome mean ± SD)	p	Between	Group Comp	arisons [‡]
Outcome Type of Support	Conco	rdant	Discordant		r	
Type of Support _	Independent	Dependent	Not Independent/ Under-Supported	IN vs DE	IN vs US	DE vs US
CESD						
[†] Instrumental	13.98 ± 11.18	13.13 ± 9.65	22.79 ± 10.09	NS	***	***
[†] Emotional	10.04 ± 8.75	12.59 ± 9.92	23.88 ± 9.89	NS	***	***
[†] Informational	12.22 ± 9.61	11.85 ± 8.75	22.53 ± 10.76	NS	***	***
SWLS						
[†] Instrumental	24.31 ± 7.30	23.82 ± 6.63	18.41 ± 7.26	NS	***	***
[†] Emotional	24.22 ± 8.41	24.73 ± 6.57	19.07 ± 6.49	NS	***	***
[†] Informational	24.05 ± 7.98	24.88 ± 6.39	19.50 ± 6.64	NS	***	***
IIRS						
[†] Instrumental	1.93 ± 1.13	2.78 ± 1.34	3.58 ± 1.49	***	***	***
[†] Emotional	1.79 ± 1.04	2.52 ± 1.31	3.44 ± 1.46	***	***	***
[†] Informational	1.95 ± 1.00	2.58 ± 1.41	3.45 ± 1.50	NS	***	***

 20.41 ± 3.79

 20.12 ± 3.77

 20.83 ± 3.82

Table 12.Outcome scores by independence group & support type, Recreation
and Social Activities domain, n = 133

Notes: SD = standard deviation

[†]Instrumental

[†]Informational

[†]Emotional

MOI

 \dagger pre hoc F-test across all three groups significant at p < 0.05

‡ IN - Independent; DE - Dependent; US - Not Independent/Under-Supported

 23.06 ± 4.11

 23.73 ± 3.92

 24.03 ± 3.56

*** Difference in means significant at p < 0.05

 24.48 ± 5.68

 25.70 ± 6.27

 24.43 ± 5.74

4.2.2.2 Domains of Discordance and Well-Being and Appraisal Outcomes

In order to generate additional information related to potential well-being, respondents were grouped according to the number of life domains where they experienced a discordant relationship (Not Independent or Under-Supported). **Figures 6, 7, 8** and **9** present box-plots of the mean well-being outcome scale scores and number of discordant domains for each support type. The boxes indicate the interquartile range while the vertical bars show the minimum and maximum observations (excluding outliers).

All four figures illustrate a general trend where, as the number of discordant domains increases, well-being outcomes are poorer. For example, **Figures 6** and **8** show that, as the number of discordant domains increases, depressive symptomatology and illness intrusiveness are greater. Additionally, we see that those with even one domain of discordance have mean CESD scores approaching or have reached the stringent cut-off of ≥ 23 for depression. Similarly, after two domains of discordance mean SWLS scores fall below the threshold for average (scores between 15 and 24) and low (scores between 5 and 14) life satisfaction. **Figures 7** and **9** show that life satisfaction and positive meaning of illness scores are lower with a greater number of discordant life domains. Mean IIRS scores approach and exceed the study cut-off for high intrusiveness around three domains of discordance. The MOI plot does not exhibit a clear cut-off, though the trend toward lower scores at higher numbers of discordant domains is still seen.



Figure 6. CESD scale scores vs number of discordant domains, by support type, n = 105



O ----- Outlier









Figure 8. IIRS scores vs number of discordant domains, by support type, n = 107





Figure 9. MOI scores vs number of discordant domains, by support type, n = 103



O ----- Outlier

4.2.3 Factors Associated with Independence Group

Multinomial logistic regression examined demographic, clinical and social network variables and their associations with the independence groups for the employment and education, family relationships, and recreation and social activities domains (**Tables 13** – **18**). Complete model-building methods have are described in **section 3.3.2.3: Model-Building Strategy**. The final models, which include variables associated with independence group (p < 0.2 on the Wald test) for the education and employment, family relationships, and recreation and social activities domains are presented in **Tables 13**, **15** and **17**, respectively. **Tables 14**, **16** and **18** show the associations (odds ratios and 95% confidence intervals) between each variable and independence group in the employment and education, family relationships, and recreation and social activities domains, respectively. **Data** for the other domains can be found in **APPENDIX IX**.

Across domains and support types, reporting less fatigue was the variable most commonly significantly associated with being in the Independent group. Being younger, having greater annual household income and availability of support (more support compared to the Not Independent/Under-Supported, less support compared to the Dependent) as measured by the MOS-SS were also significantly associated with being in the Independent group in most cases. Other factors significantly associated with independence group varied by domain and type of support and included being married vs unmarried, not having recent activity or flare, pain and LSNS score. A number of factors were not significant in any domains for any support types, and were not included in any of the final models. These included higher level of education, being involuntarily out of work, disease duration, and having no recent flares.

Table 13.Final multinomial logistic regression models: Demographic, clinical & social network variables associated with
Independence group (p < 0.2 on the Wald test) - Employment & Education domain, n = 116</th>

Voriable	Instrumental Support		Emotional Support		Informational Support	
variable	Wald Statistic	p-value	Wald Statistic	p-value	Wald Statistic	p-value
Demographic Characteristics						
Age, Years	4.78	0.0917	3.46	0.1770		
Married						
≥High School						
Annual Household Income ≥ \$70K			3.41	0.1821		
Involuntarily out of Work						
Clinical Characteristics						
Disease Duration, Years						
No Flare past 3 months						
Current Remission					6.20	0.0450
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS					3.45	0.1783
Fatigue past 3 months, 10-pt VAS	18.59	< 0.0001	11.74	0.0028	6.09	0.0476
Symptom Severity Since Diagnosis, 10-pt VAS					4.28	0.1178
Social Network Characteristics						
MOS Social Support Scale	10.22	0.006	12.08	0.0024	10.13	0.0063
Lubben Social Network Scale						

Note: only variables with Wald and p-value data are included in the each model

Table 14.Multinomial logistic regression models (variables significant overall at p < 0.05): Association (odds ratios and
95% confidence intervals) between demographic, clinical and social network variables and Independence group
- Employment and Education domain, n = 113

Variable	Instrumer	Instrumental Support Emotional Support		Information	al Support	
variable	IN vs DE	IN vs US	IN vs DE	IN vs US	IN vs DE	IN vs US
Demographic Characteristics						
Age, Years	1.03† (1.00, 1.06)					
Married						
≥ High School Education						
Annual Household Income ≥ \$70K						
Involuntarily out of Work						
Clinical Characteristics	<u> </u>				u	
Disease Duration, Years						
No Flare past 3 months						
Current Remission						
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS	1.20† (1.02, 1.40)	1.52‡ (1.25, 1.85)	1.38‡ (1.08, 1.75)	1.55‡ (1.21, 1.99)		1.20† (0.99, 1.47)
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics	- -				u	
MOS Social Support Scale, higher scores = more support available			1.12† (1.01, 1.25)		1.13† (1.01, 1.27)	
Lubben Social Network Scale, higher scores = larger/closer networks						

IN: Independent, DE: Dependent, US: Not Independent/Under-Supported

Pr > Chi Square: p < 0.05; p < 0.01

V	Instrumental S	Support	Emotional Su	ıpport	Informational S	Support
variable	Wald Chi Square	p-value	Wald Chi Square	p-value	Wald Chi Square	p-value
Demographic Characteristics	<u>n</u>		H			
Age, Years	4.85	0.0886	6.04	0.0489	11.07	0.004
Married			6.26	0.0436		
≥High School						
Annual Household Income ≥ \$70K	3.45	0.1782	5.10	0.078	4.87	0.0876
Involuntarily out of Work						
Clinical Characteristics	0		n		n	
Disease Duration, Years						
No Flare past 3 months						
Current Remission						
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS	14.93	0.0006	4.98	0.0831	13.69	0.0011
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics					ш 	
MOS Social Support Scale, higher scores = more support	11.35	0.0034	11.87	0.0026	11.83	0.0027
Lubben Social Network Scale, higher scores = larger/tighter networks			3.84	0.1466		

Table 15.Final multinomial logistic regression models: Demographic, clinical & social network variables associated with
Independence group (p < 0.2 on the Wald test) – Family Relationships domain, n = 112</th>

Note: only variables with Wald and p-value data are included in the each model

Table 16.Multinomial logistic regression models (variables significant overall at p < 0.05): Association (odds ratios and
95% confidence intervals) between demographic, clinical and social network variables and Independence group
- Family Relationships domain, n = 112

Variable	Instrumen	tal Support	Emotion	al Support	Information	al Support
variable	IN vs DE	IN vs US	IN vs DE	IN vs US	IN vs DE	IN vs US
Demographic Characteristics						
Age, Years					1.04† (1.00, 1.08)	
Married		0.11† (0.02, 0.82)		0.04‡ (0.01, 0.33)		
≥High School						
Annual Household Income ≥ \$70K			11.20† (1.62, 77.36)	10.02† (1.40, 72.19)		3.20† (1.03, 9.90)
Involuntarily out of Work						
Clinical Characteristics			0			
Disease Duration, Years						
No Flare past 3 months						
Current Remission						
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS	1.20† (1.03, 1.40)	1.81‡ (1.32, 2.49)				1.44‡ (1.80, 1.74)
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics						
MOS Social Support Scale, higher scores = more support available		0.85† (0.74, 0.98)			1.14† (1.02, 1.27)	
Lubben Social Network Scale, higher scores = larger/tighter networks						

IN: Independent, DE: Dependent, US: Not Independent/Under-Supported

Pr > Chi Square: †p < 0.05; ‡p < 0.01

Table 17.	Final multinomial logistic regression models: Demographic, clinical & social network variables associated with
	Independence group (p < 0.2 on the Wald test) – Recreation & Social Activities domain, n = 124

Variable	Instrumental Support		Emotional Support		Emotional Support	
	Wald Chi Square	p-value	Wald Chi Square	p-value	Wald Chi Square	p-value
Demographic Characteristics						
Age, Years	8.72	0.0127	6.71	0.0348	8.15	0.017
Married						
≥High School						
Annual Household Income ≥ \$70K	7.08	0.0291				
Involuntarily out of Work						
Clinical Characteristics						
Disease Duration, Years						
No Flare past 3 months						
Current Remission						
Activity past 3 months, 10-pt VAS	6.40	0.0409				
Pain past 3 months, 10-pt VAS			4.82	0.0897	4.08	0.1298
Fatigue past 3 months, 10-pt VAS	14.55	0.0007	12.63	0.0018	5.72	0.0574
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics	1		1			
MOS Social Support Scale, Higher scores = more support	10.64	0.0049	19.67	< 0.0001	7.90	0.0193
Lubben Social Network Scale, higher scores = larger/tighter networks						

Note: only variables with Wald and p-value data are included in the each model

Table 18.Multinomial logistic regression models (variables significant overall at p < 0.05): Association (odds ratios and
95% confidence intervals) between demographic, clinical and social network variables and Independence
group – Recreation and Social Activities domain, n = 124

Variable	Instrumental Support		Emotional Support		Informational Support	
	IN vs DE	IN vs US	IN vs DE	IN vs US	IN vs DE	IN vs US
Demographic Characteristics						
Age, Years	1.04† (1.01, 1.08)					0.94 ‡ (0.92, 0.99)
Married						
≥High School						
Annual Household Income ≥ \$70K		6.14‡ (1.61, 23.38)				
Involuntarily out of Work						
Clinical Characteristics						
Disease Duration, Years						
No Flare past 3 months						
Current Remission						
Activity past 3 months, 10-pt VAS		0.69† (0.49, 0.98)				
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS		1.75‡ (1.31, 2.34)	1.56‡ (1.19, 2.04)	1.60‡ (1.21, 2.12)		1.26† (1.04,1.53)
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics			-			
MOS Social Support Scale, higher scores = more support available		0.86‡ (0.77, 0.97)		0.85 ‡ (0.76, 0.96)	1.12† (1.01,1.24)	
Lubben Social Network Scale, higher scores = larger/tighter networks						
IN: Independent, DE: Dependent, U Pr > Chi Square: $\dagger p < 0.05$; $\ddagger p < 0.05$	S: Not Independent	t/Under-Supported				

5.0 DISCUSSION AND CONCLUSIONS

5.1 Overview of Major Findings

This study addresses gaps in the current literature on the social support experiences of women with lupus. Specifically, it examined the experiences of women with lupus in receiving support and their evaluations of that support for three separate support types across five life domains. Participants were grouped into independence groups using their evaluations of their support, and associations with well-being, health appraisals, and other variables were examined. The findings highlight the complexity of support within and across individuals. Social support is considered a modifiable factor that can influence health appraisals and well-being and, in this context, we often assume that social support should be increased in order to increase its benefits. However, this study found that support needs and evaluations varied, and it was a mismatch between the support provided and the actual needs of women with lupus that was related to decreased wellbeing. The study drew on a sample of women of different ages presenting a variety of demographic, clinical, and social network experiences. Findings were consistent across the life domains examined, across different types of support, and using diverse methods of measuring well-being. As a result, they provide good initial data suggesting that social support may not need to be maximized, but rather tailored to each individual's specific needs and desires, in terms of the amount of help and support needed in order to enhance the potential for well-being benefits.

Though the overall response rate for the survey was lower than anticipated (approximately 24%), the final sample size of 163 individuals makes this one of the

larger studies of women with SLE that has examined social support and well-being. Moreover, it presents a detailed examination of social support in terms of how it is evaluated by the recipient and is, to our knowledge, the first to examine how these evaluations relate to well-being and health appraisals. The questionnaire included several standardized measurements, as well as a novel set of questions to un-pack social support experiences. The variety of validated measures, as well as novel and detailed support questions provided a more detailed investigation of support than in previous research with women who have lupus.

Further discussion and contextualization of specific findings are presented for each of the study objectives. First, the division of the sample into independence groups in each domain and for each support type (objective one) is discussed. This is followed by a discussion of the difference in well-being and appraisal measures across these independence groups, as well as the changes in well-being measures based on the number of life domains with discordant support relationships (objective two). Finally, a discussion of several demographic factors, lupus-related clinical features, and social network characteristics and their associations with social support and well-being and appraisals (objective three) is presented. The findings of this study have several implications for researchers, clinicians, and women with SLE and their families. These are proposed throughout the discussion, and a summary of important applications and future directions is presented in a separate section, followed by the ultimate conclusions of this study.

5.2 Interpretation and Contextualization of Findings

5.2.1 Description of Independence Groups (Objective One)

The women with SLE in this sample were diverse in the nature of the social support they needed and in their perceptions of whether the support provided to them (or the absence of support) was appropriate to their needs. This is in keeping with our hypothesis that support experiences are individual-, domain- and support type-specific. These differences also echo previous findings that individuals may be satisfied with support in one or some areas of life, but not others (Vennhoven, 1984). The findings of this study expand on this previous research to explicitly examine satisfaction with the amount of support received in each domain. Typically, about half of the sample (43 - 54%) was satisfied with the amount of different types of support received (or not received) in all areas of life studied. The remainder however, experienced insufficient support in at least one area. Few women experienced dissatisfaction in all five domains studied, though the proportion reached as high as 13.5% of the sample for emotional support.

The clustering of individuals into independence groups within each domain and for each support type revealed a great deal about the sample. Many of the women in this study were identified as Independent in every domain assessed. This may be attributable to the average low disease activity at the time of evaluation (90% either in remission or experiencing only mild activity) high level of education (about 70% completed undergraduate college or university, or higher) and high incomes (about 50% with annual household incomes over \$70,000) seen in the sample as a whole. These same characteristics have been identified as being determinants of better health in the general Canadian population (Mikkonen & Raphael, 2012). However, it is also important that

while the lack of support these participants received may be appropriate given their present circumstances, it may make them vulnerable to becoming Not Independent or Under-Supported if their support needs increase and support is not available. Given that SLE is a disease characterized by periods of remission and flare, such a fluctuation of needs over time is likely for at least some individuals. At the same time, descriptive results of the social network characteristics in the sample show that participants typically had large, cohesive social networks, with a mean Lubben Social Network Scale (LSNS) score of 32 of a possible 50, and high levels of perceived available support, with a mean MOS-Social Support Scale (MOS-SS) of 21 out of a possible 36. This suggests that many respondents may have the support resources available to meet additional support needs that may arise.

In some domains and for some types of support, the Dependent group (those with support needs being met by others) was the largest group. Many individuals who needed help perceived that it was available and were utilizing it. Only one individual reported receiving excessive support (i.e. in the Imposed Dependence group). As such, it seemed that when support was available, it was valued and utilized by women in this sample. The findings of this research also fit in the context of Gignac and co-authors' work in arthritis (Gignac *et al.*, 2000; Gignac *et al.*, 2012). Specifically, their studies suggested that dependence may be an adaptation that allows for time and energy to be focussed on more important or more highly-valued activities. If an individual feels in control of the extent to which they rely on others, then self-regulated or self-directed dependency may, in fact, be an adaptive process that promotes health management (Baltes, 1995). That being said, Dependent individuals, or those who use dependence as an adaptation, may be vulnerable

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to becoming Not Independent or Under-Supported if support resources are reduced or exhausted, or if support needs increase but support resources cannot rise to meet the need. Future research needs to examine the long-term maintenance of support resources and changes in support and well-being.

As noted, only one participant reported that they received unnecessary support (i.e. having Imposed Dependence in 2 of 15 domain-support type scenarios). It may be that Imposed Dependence is rare case in women with lupus, especially younger women. Gignac and Cott (1998) developed their conceptual model of independence and dependence in adult-onset chronic physical illness aimed largely at older adults. The women in the present sample were middle aged, on average, which is a time of life when others don't expect to provide an individual with large amounts of ongoing assistance. As such, the women in this study who didn't need assistance were not overwhelmed by unwanted help. Additional research is needed into Imposed Dependence, particularly examining different age groups and whether some types of support (e.g., instrumental support) are more likely to be perceived as unwanted and impinging on independence than other types of support (e.g., emotional support).

Employment and Education Domain

The majority of women in the sample were Independent in terms of instrumental support (43%) in the employment and education domain. The lack of desire or need for instrumental support related to employment and education may be an extension of the low disease activity and low degree of disability, and high rate of employment in the sample. It is more likely however, that asking for or receiving large amounts of ongoing instrumental support in a professional workplace setting is not feasible. Help may be even

less likely related to education. In these areas of life, individuals may need to give up or reduce the time spent at work or in school if lupus symptoms flare or persist. More research is needed, but referrals to occupational or physical therapists may also be helpful to women with lupus as an alternate means of support, in terms of increasing physical abilities to perform instrumental tasks and providing alternatives and adaptations. Needs for emotional and informational support were noted more frequently than needs for instrumental support in the employment and education domain. The desire for emotional support related to employment and education in the sample (52% Dependent and 31% Not Independent or Under-Supported) may reflect the absence of opportunities for instrumental support, the uncertainty of living with lupus from day-to-day and the use of emotional support as a coping strategy to handle the stresses of the unknown, as well as a variety of work and education tasks and activities that can be difficult for people with lupus to manage. Many of the women in this sample were physically healthy and were working currently (43.5%). However, increases in their disease activity, changes in their jobs, or changes in their current levels and types of support may relate to changes to their working status or workplace dynamics. There is limited information about work adaptations and support related to maintaining employment, which is important given that nearly 42% of women in this study reported being Not Independent or Under-Supported in terms of informational support in this domain. Both formal workplace support programs and clinical support, as well as informal support from colleagues, family and friends are likely to be important. Psychotherapy, education and workplace interventions may address the gaps in emotional and informational support for those without adequate informal resources.

Family Relationships Domain

The family relationships domain was an area where participants often reported needing different types of support, and many participants reported receiving the support they needed. As such, the Dependent group was the largest for all types of support. Where support problems were reported, it was in not receiving enough emotional support (about 22% of women). This may be because of the invisible and unpredictable nature of lupus, which makes providing support difficult for family members, as they don't always know or understand how a person with lupus is feeling from day-to-day. Not only may support needs among individuals with lupus change without family and friends being aware, but support providers will also have their own stressors that could make providing ongoing support difficult. Gauging support may also be difficult if the person with lupus does not disclose their support needs on an ongoing basis. These findings are in keeping with previous research that finds that negative interactions in support relationships are more likely to occur with family than with those in more distal relationships (i.e., friends, colleagues) (Schuster et al., 1990; Himes & Reidy, 2000). Research with individuals living with lupus and their family members would be helpful in identifying areas where support provision is difficult, as well as in identifying strategies to better communicate around support.

Recreation and Social Activities Domain

The recreation and social activities domain was somewhat different from the other two domains in that the majority of study participants were Dependent for instrumental support and emotional support, but Independent for informational support. That is, women with lupus did not report needing information about social and recreation

activities. Instead, they needed instrumental support (e.g., someone to drive them to an activity or a friend's house) and emotional support (e.g., such as someone to listen to concerns about no longer being able to participate in social and recreational activities as in the past). This makes sense intuitively.

The recreation and social activities domain was often ranked as a priority by respondents (APPENDIX IX). This supports previous research findings that discretionary activities are important and may be associated with perceptions of greater independence (Katz & Yelin, 1995; Ditto et al., 1996; Gignac & Cott, 1999; Gignac et al., 2000; Katz & Yelin, 2001; Neugebauer et al., 2003; Gignac et al., 2006; Reinseth & Espnes, 2007; Gignac et al., 2008; Gignac et al., 2012; Kaptein et al., 2012; Liddle et al., 2012). Valued life activities have also been found to be important for those with SLE in terms of health perceptions and psychological well-being, even when assistance is required to maintain participation in these activities (Katz et al., 2008; Janke et al., 2009; Katz et al., 2009). In fact, between 1/3 and 1/2 of the sample, depending on support type, were in the Dependent group, and were receiving assistance or support to maintain participation in this domain. More than 1/4 of respondents were not receiving the support they felt they needed in this domain. This finding has particular implications to occupational therapists and other clinicians, who may want to work with patients to help them maintain or improve their participation in discretionary activities, not just activities of daily living, employment or education.

Summary: Description of Independence Groups (Objective One)

- Support needs and experiences varied within and across women by domain and support type.
- Many women in this study were Independent across all domains, but Dependent relationships were also prevalent, indicating that support is often desired and available when needed.
- Despite high availability of support across the sample, many women needed help but did not receive it. This was especially true in the employment and education domain.
- Informal instrumental support may not be appropriate for needs related to work and school, but emotional and informational support from friends and family is important to individuals living with lupus in this domain.
- Emotional support is also important in maintaining and participating in Family Relationships
- Psychotherapy, educational and workplace interventions may address the gaps in emotional and informational support for those without adequate informal resources
- Social and recreational activities are important to women with lupus, and many rely on instrumental and emotional support in this domain to manage the difficulties they experience with it.

5.2.2 Well-Being and Appraisals and their Relationship to the Independence Groups and Concordant/Discordant Support (Objective Two)

This study drew upon four markers of psychological well-being and health appraisals, referred to collectively as "well-being". The measures, which are theorized in the literature to capture aspects of psychological wellness in the context of illness, included the Centre for Epidemiologic Studies Depression scale (CESD), the Satisfaction with Life Scale (SWLS), a modified Illness Intrusiveness Ratings Scale (IIRS), and the Meaning of Illness scale (MOI). The descriptive data for the well-being and appraisal outcome variables was similar to the results of previous studies, where the well-being of many of those with SLE is poorer than the general population (McElhone *et al.*, 2006). In this study, 25% of respondents met the criteria for depression (CESD \geq 23 out of 60), about 20% were dissatisfied with their lives (SWLS < 14 out of 35), and 21% reported high intrusiveness (average IIRS > 4 out of 14). Only small percentage of the sample met criteria for negative meaning from living with lupus (~17%% \leq 1 standard deviation below the mean), though few reported positive meaning (~16% \geq 1 standard deviation

In examining support needs and receipt of support, we found that the majority of participants described being in concordant supportive relationships (67 – 89% of the sample, depending on domain and support type examined). The concordant group represented women who were both Independent (and not receiving support) as well as those who were Dependent (needing and receiving support). Although their experiences were quite different related to support, they were theorized to be similar in that they have their support needs met, whether the need was to be provided support or not. Discordant relationships, where support needs exceeded the support received, were by no means rare,

and represented up to a third of the sample depending on the domain and support type. In fact, half of the sample had discordance between their support needs and the support they received in at least one life domain, indicating a significant gap between what is needed and what a social network is able or willing to provide. This highlights the potential vulnerability of the Independent and Dependent groups to becoming Not Independent or Under-Supported if support needs or resources change. Additional longitudinal research examining these changes and their effects is needed.

The results of this study were consistent in showing similarly high levels of well-being among women who were Dependent and women who were Independent. Both groups reported significantly greater well-being than those who were Not Independent or who were Under-Supported, in most instances. Additionally, those with greater numbers of discordant domains exhibited lower well-being. Particularly interesting was that when looking at depression and life satisfaction scores, only one or two domains with discordance between need and receipt of support was necessary to meet thresholds for presence of depression and low life satisfaction or dissatisfaction with life.

These findings are novel in lupus and are particularly interesting in the context of previous independence research, which tends to describe independence in terms of positive adjectives, such as autonomy, control and self-regulation, while dependence is postulated to be the opposite and assumes negative connotations (Lawton, 1981; Wahl, 1991; Kaufman, 1994; Marshal *et al.*, 1995; Baltes, 1996). The results of this study highlight that what is important is that needs are met, and the mere presence of a need does not necessarily indicate a negative outcome. Additionally, it seems that specific needs must be met in most or all areas of life in order to maintain ideal levels of well-
being. This is of particular interest in this sample, where half of individuals had discordance in at least one life domain. Future research, particularly studies involving support interventions, need to better take this into account. For example, interventions might be more effective if they first characterized specific support needs (type of support, area of life, even specific tasks) and then, working with individuals who have lupus, helped to identify strategies and supports aimed at meeting those needs. This could include coaching of support providers, improvements to access to formal support, and education.

Summary: Well-Being and Independence Groups/Concordance (Objective Two)

- Many respondents reported that their overall well-being was good. However, about 20 - 25% met criteria for depression, low life satisfaction, and considerable illness intrusiveness.
- Having support needs met, regardless of whether an individual was Independent or Dependent, was associated with similar high well-being scores, which were significantly better than individuals who were Not Independent/ Under-Supported.
- Those with concordance between support needs and receipt of support reported better well-being than those with discordance between support needs and receipt of support.
- Future research and interventions should include family members in identifying strategies to educate and improve communication, with the goal of improving support provision and matching support provided to specific support needs.

5.2.3 Independence and Demographic, Clinical, and Social Network Characteristics (Objective Three)

Few demographic, clinical, or social support variables exhibited consistent associations with the different independence groups, despite theoretical and research evidence for inclusion of these variables based on the previous social support literature.

5.2.3.1 Factors Associated with Independence Group

Fatigue

Fatigue stood out as a factor consistently associated with the independence groups across domains and support types. Those with lower fatigue were more likely to be in the Independent group compared to the Dependent and Not Independent/Under-Supported groups. This highlights the importance of fatigue both to functioning and diverse types of support, including instrumental, emotional, and informational support. Lower fatigue may enable individuals to function more independently and need less help, support and information, whereas greater fatigue may give rise to greater need for support of all types. Fatigue is also a particularly interesting factor to examine because it is generally invisible to others. Individuals requiring assistance because of fatigue may need to explicitly ask for help, as compared to those with more overt signs of illness which may elicit recognition and prompt offers of support. In line with these findings is a study of individuals with rheumatoid arthritis that found that when fatigue was underestimated by a spouse, the perception that the individual was receiving problematic support increased (Lehman *et al.*, 2011). This study extends previous research and highlights that many people received different types of support (i.e., were Dependent and got the support they needed) while others reported being Not Independent or Under-Supported. Also of

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interest for future research is that fatigue can vary greatly from day-to-day. As a result, individuals may require assistance because of fatigue at some times but not others; and providers of support have challenges in being sensitive to this invisible and fluctuating symptom. This points to the need for ongoing communication between patients, family members and others providing support to discuss explicitly what types of support are needed and in what domains. It also has important implications for clinicians treating women with SLE. Fatigue is commonly reported (Krupp *et al.*, 1990; Tench *et al.*, 2000; Overman *et al.*, 2015), but is often not captured by clinical and research tools designed to evaluate disease activity. As a result, clinicians may not only be missing important disease information that is relevant to women with lupus, they may be missing those who are in need of interventions and are under-supported or in distress.

Age

It was expected that older respondents might have greater needs for support, as has been found in studies with the general population (Parker & Thorslund, 2006), and that they might also have more unmet needs, or discordant support relationships (Danoff-Burg & Friedberg, 2009). However, we found only limited evidence for this in the current study. Members of the Independent group were often younger than members of the Dependent and Not Independent/Under-Supported group. However, age did not meet statistical significance in multivariable analyses in many cases. This suggests that age is a proxy for other factors – like fatigue and other health variables or the availability of a support network. It is these latter variables that may need greater attention related to support interventions that address modifiable risk factors rather than age, *per se*.

Annual Household Income

Similar to age, the findings for income were not consistent, but suggested some association with independence grouping. In general, Independent individuals were more likely than Dependent or Not Independent/Under-Supported individuals to have annual household incomes over \$70,000 per year. The cross-sectional nature of the data makes it impossible to tease out the direction of the findings. The greater support needs of those who are Dependent and Not Independent/Under-Supported may mean that they have greater difficulties in earning an income, and as a result have a lower household income. More unexpected however, was that the benefits of a higher income came mostly in the family domain (and not employment and education or recreation) and were associated not with instrumental support, but with greater emotional and informational support, especially among those in the Independent group. It may also be that greater financial resources enables individuals to access timely and better care and provide more information and emotional support (Waters et al., 1996; Kasitanon et al., 2000; Gignac et al., 2012). This may be an aspect of lupus that is of particular interest to women in the Independent group. Their ability to function independently may mean that less of their income is focused on instrumental help and, instead, more of their resources are devoted to emotional support like psychological support or additional disease information.

5.2.3.2 Factors Not Related to Independence Group

Demographic Variables

Interestingly, a number of variables that were expected to be associated with the independence groups were not found to be significant. This may have been related to

sample size and having insufficient statistical power available to differentiate the three independence groups across the different domains and types of support. For example, it was predicted that marital status (specifically being unmarried) would exacerbate the discordance between what is needed and what is received, since there is evidence in the general population that being married is predictive of higher levels of social support (House *et al.*, 1988; Barrett, 1999; Mastekaasa, 1994; Sherbourne & Hayes, 1990). However, there are recent studies like De Paulo and Morris (2005) that don't find positive impacts of marital status and suggestions in the literature that in an increasingly connected world, the importance of being married has declined (De Paulo & Morris, 2005; Shapiro & Keyes, 2007; Holt-Lunstad *et al.*, 2008). Extensions of the present research in SLE may benefit from identifying individual members of social circles and what, when, and how they provide different types of support.

Self-Reported SLE-Related Clinical Variables

It was assumed that those with lower disease activity and fewer flares would be more likely to be Independent, presumably because of fewer stressors, limitations and needs (Karlson *et al.*, 1997; Dobkin *et al.*, 1998; Ward *et al.*, 1999; Alarcon *et al.*, 2001; Alarcon *et al.*, 2006). However, better current disease state did not significantly contribute to understanding support differences in different domains. Additional research is needed. The findings may relate to the relatively low levels of current disease activity in this sample. In particular, longitudinal research that captures both acute symptoms and especially flares, as well as chronic problems may better capture differences among the independence groups in different types of support. There are also additional measures of lupus disease activity, severity, and damage, in particular those completed by physicians, which may be worth investigating in terms of whether they can discriminate between individuals' different support experiences.

Available Social Support and Social Networks

Across domains, few differences were seen in emotional support related to the social support scales. It seems that the quality of support received influences evaluations, rather than having a greater quantity of support and/or support-providers. We don't see any differences using the Lubben Social Network Scale (LSNS). The LSNS captures both the size of the network and the quality of support. It may be that the measure was not sensitive to differences between the groups or that the inclusion of both support measures meant there was shared variability in support.

Across the domains presented (employment and education, family relationships, and recreation and social activities) there is a significant difference between the Independent and the Dependent groups in terms of informational support, with greater MOS-Social Support scale (MOS-SS) scores being associated with more informational support among those who are Dependent. If informational support is available, it is of more value to those who are Dependent than Independent because of their needs.

In the family relationships and recreation and social activities domains there were significant differences between those who are Independent and Not Independent/Under-Supported in terms of instrumental support, in that we see greater MOS-SS scores being associated with less instrumental support among those who are Not Independent/Under-Supported. Those who are Independent do not need this support and are not receiving it, but perceive it to be available if needs change.

These MOS-SS results provided a proof-of-concept that the Dependent are supported and the Independent and Not Independent/Under-Supported are not. Any results using the MOS-SS must be taken with caution, however, since the majority of scale items assess the availability of emotional support, with less consideration given to instrumental or informational support. Though, as discussed earlier, there was greater need for emotional support than instrumental support in the sample, greater MOS-SS scores may not capture the availability of support in many circumstances. This again highlights the limitations of global measures that do not examine the details of needing and receiving different types of support separately. Further validation of detailed measures, such as the one used in the present study, will provide better indicators of support experiences.

Summary: Demographic, Clinical and Social Network Factors Associated with Independence Groups (Objective Three)

- Fatigue was a significant factor in differentiating the Independent group from the other groups across different domains and types of support. Greater fatigue may precipitate support needs of all types – instrumental, emotional, and informational, across all domains of activity.
- Higher incomes may protect against the need for informal instrumental support related to family relationships; lower income individuals may have increased need for social support.
- Dependent individuals perceive higher levels of available emotional support related to employment and education and family relationships than Independent individuals, and more informational support than Independent individuals related to recreation.
- Not Independent/Under-Supported individuals perceive less instrumental and emotional support than Independent individuals, though the Independent do not currently need or utilize it.
- Many demographic and clinical factors were not significant in differentiating the independence groups across different domains of activity and needs. Additional research with a larger sample size is needed.

5.4 Summary of Applications and Recommendations

The present study provides evidence for the value of including greater depth and breadth in patient evaluations of their support needs and experiences. Of particular benefit in future studies would be the creation of an enhanced social support measure that takes into account different domains and types of support, as well as evaluates whether support needs are met. For example, one of the findings of this study pointed to the value that women placed on a range of activities, including social and recreational activities, which have often been ignored by clinicians in favour of personal care activities. Receiving instrumental and emotional support in this area was important as well as diverse types of support for work, education and family activities. Future studies should also include: a) larger, more representative samples of women and men with lupus from more diverse clinic settings to enhance the generalizability of findings and compare women and men; b) studies of support in other chronic illnesses, with priority given to other systemic autoimmune rheumatic diseases for comparison; and c) larger more diverse samples to capture an Imposed Dependence group of individuals who feel that they are receiving unwanted support. It would be useful to compare the well-being of this group compared to the other independence groups.

Investigations of how social support needs and availability change over time, what the barriers may be to accepting or providing support, and how informal and formal support resources intersect - especially whether government services can supplement informal resources like instrumental help - would further enhance our understanding of the interrelated concepts of independence, support, and well-being. In addition, the findings of this study and those of other research would be helpful in designing and tailoring new

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interventions. For example, future studies could include an interventional component designed to evaluate specific types of social support in diverse domains and support provision tailored to gaps in support. This type of intervention may include the development and validation of tools for lupus patients and their social networks to help detail support needs and determine helpful and feasible ways for these needs to be met. This study also points to important considerations for clinicians treating women with lupus. Identifying patients who are struggling with the impact of their disease and helping them better self-manage their condition or get additional support or psychological help to improve their well-being is an important treatment goal in addition to physically managing the disease. Asking patients about whether their support needs are being met or whether they have unmet needs that are challenging to them may help clinicians initiate conversations about well-being that can lead to important referrals for additional and complementary treatment. Physicians may already identify these problems in some of their patients, but the current medical system may present barriers to access to these resources for the patient. It is imperative that medical care systems allow for access to these much needed resources for persons with chronic diseases like lupus.

It may also be important to include others, like family members, in the treatment process. Interventions that provide coaching of support providers, new strategies or tools for selfcare (e.g. access to personal medical records, tools to track laboratory results, medications etc.), or supplementation of informal support with formal support resources (e.g. therapists, counsellors, etc.) may be helpful, not only for the patients' well-being, but also for the well-being of potentially over-loaded family members. The study findings highlight the importance of personalizing support and working through different domains of life and types of support that may be needed. In cases where inclusion of family and friends is not wanted or possible, social workers, counsellors, human resource professionals or others may be able to provide specific types of support outside of a health care facility.

Finally, the results of this study suggest that communication is critical for women with SLE. Lupus symptoms are often invisible and intermittent. That can mean that it is difficult for others to gauge support needs. Findings showed that there were often high levels of support provided when help was needed. Individuals need to feel comfortable articulating their problems and limitations to members of their social networks on an ongoing basis, and need to be specific about the resources they believe they need to meet their needs. As noted, research to develop new tools to assist in this process may be helpful and may help to maintain well-being.

Summary: Applications and Future Directions

Researchers

- Future research should consider measuring support needs, experiences and evaluations with a new, detailed support measure.
- Future research directions include longitudinal studies, male and female SLE patients recruited from multiple centres and other systemic rheumatic diseases and chronic conditions.
- Social and community health research should focus on ways to supplement informal support in settings outside of health care.

Clinicians

- Current disease measures may need expanding to fully capture the symptoms of lupus like fatigue that impact women's everyday lives and support networks and which may signal vulnerability to decrements in well-being.
- Referrals to therapists, social workers and counsellors are important when social support is needed or insufficient to meet patient needs.
- Informal support providers should be included in treatment plans, and interventions and tools designed to help provide them with strategies to help family members with lupus.

Health Care Systems

 Creation of integrated multi-disciplinary clinics and trajectories of care for patients with lupus would facilitate access to specialized health professionals and related services, helping to ensure needs are met.

Women with SLE and their Social Networks

- Maintenance of social ties is important, even if there is no current need for specific support.
- The fluctuating nature of lupus and its often invisible symptoms makes communication an important aspect of social support; women with SLE and their friends and families may need tools or training for sharing difficulties and needs.

5.3 Study Strengths and Limitations

This is the first comprehensive study combining the concepts of support, independence, and well-being in lupus. While these issues have certainly been studied to various extents (as presented in the preceding review of background and supporting literature), there have been no quantitative, larger-scale explorations of how all of these concepts are related to one another in SLE.

This is also the first study in lupus to not only assess available social support, but to also include an individual's evaluations of whether support was desired, whether it was sufficient in terms of the type of support provided, and in what domain of life. A number of studies in SLE have not found evidence for a significant association between social support and well-being. This may be due to the use of global scales and the assumption that all available support is utilized and valued. It may also be related to the use of global health-related quality of life measures, instead of more specific measures of well-being and disease appraisal, which may provide a more comprehensive understanding of the impact of lupus on the lives of women.

This study builds on a body of research discussing social support, independence and wellbeing in chronic illness. It was designed with a strong theoretical and evidence-based conceptual framework through a thorough *pre hoc* examination of the nature and potential interactions of the concepts and variables studied using the available literature. This provided a strong basis for the study objectives and hypotheses, the design of the survey instrument and critical appraisal of the results. Future research examining support, independence and well-being in individuals with lupus and other rheumatic diseases would benefit from greater attention to theory and research in the larger support literature.

The number of respondents in the study (n = 163) provided a sample that was sufficiently large to examine the diverse relationships among variables. However, the response rate was lower than anticipated (~ 24%). Additionally, although the sample was drawn from the Lupus Clinic female cohort, it differed from the cohort with respect to several demographic characteristics. While these statistical differences were significant, the absolute differences were often small and may not have clinical relevance or bearing on the research questions at hand. For example, individuals who are 48 years old (mean Lupus Clinic age) share the same stage of life as individuals who are 51 (mean sample age), and will have many shared experiences. Similarly, the difference between 18 (mean Lupus Clinic disease duration) and 22 years (mean sample disease duration) living with lupus likely does not, in itself, imply differences in the disease experience. Having said this, the sample size differences in some characteristics may limit the generalizability of the findings. Additional research is needed to replicate and extend these findings.

Additional research is needed to validate current findings in new samples, as well as in longitudinal and intervention research designs. The cross-sectional, observational design utilized was appropriate for determining how women in the sample evaluated their social support experiences and the prevalence of unmet needs, but longitudinal analyses are required to determine the nature of the apparent relationship between support evaluations and well-being. The cross-sectional nature of this study did not allow for full evaluation of criteria to determine causality, such as the Bradford Hill Criteria (Hill, 1965). Specifically, the consistency (outside of the sample) and temporality of associations could not be determined, and experiments (interventions) were not conducted. However, the strength of associations, comparisons of associations between similar factors (wellbeing outcomes), and consistency across domains were presented, and discussions of the plausibility of possible causal relationships, and alternative explanations, based on the literature were discussed.

Finally, because no measures were available to assess the breadth of support appraisals examined in this research, new questions were created drawing on theory and studies in other chronic diseases. These questions helped illuminate differing support needs and perceptions, but require validation in other samples.

Given that this was the first study in lupus to combine social support, independence and well-being, a primary goal was to examine whether the theorized relationships among variables existed. The findings hold promise, however, longitudinal and intervention research are needed to better examine causality and change.

Summary: Study Strengths and Limitations

- This is the first comprehensive study of evaluations of support, independence and well-being in lupus.
- The study was designed using a strong theoretical framework.
- The response rate was lower than expected and there were some demographic differences between the sample and larger clinic data. Additional research is needed to replicate the findings.
- Novel items were created to examine support concepts assessed in the research. Additional research is needed to validate the measures and examine causality and change in support and well-being over time.

5.5 Conclusions

This study provides important and novel information regarding the experiences of women with SLE in needing and receiving social support across diverse areas of their lives. It contributes to a body of research that has previously focused on independence mainly in older adults. Using a cross-sectional survey, diverse evaluations of social support were examined and categorized into independence categories that described either concordance or discordance with needs. These evaluations were further examined in terms of their relationship with four different indicators of well-being, as well as a wide range of demographic, clinical, and social network variables. Findings highlight that it was not the amount of support that was always relevant, but that it may be most beneficial when it matches the support needed by the individual in terms of the type of support provided in different areas of life.

The findings from this study were encouraging in that many women in the sample reported concordant support relationships, in which their needs for support matched the support they received, and that these concordant relationships were associated with greater well-being. However, results also drew attention to the fact that discordant relationships were not rare and that well-being was lower where discordant support relationships existed, and was frequently associated with greater fatigue, especially among those whose support needs categorized them as being Not Independent.

Further research is needed to continue development of detailed support measures and enhance the theoretical basis of support in chronic diseases like lupus. Development of intervention tools or training to assist women with support and independence needs is also needed to improve support while maintaining independence. The findings suggest that clinicians need to be mindful of health factors like fatigue, as well as the broader social networks and support needs that exist for many women and how they relate to disease management and well-being. Discussion of social support systems or referral to other for support needs should be part of treatment plans. Along with this, availability and access to services and referral centres to provide this component of treatment are paramount. Women with lupus can benefit from this research and additional studies of support. The findings highlight the importance of communication and making an individual's social network aware of specific support and independence needs in different domains of life, as well as potential fluctuations in these needs.

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APPENDIX I ACR CRITERIA FOR SYSTEMIC LUPUS ERYTHEMATOSUS

Criterion	Definition
Malar rash	Fixed erythema, flat or raised, over the malar eminences, tending to
	spare the nasolabial folds
Discoid rash	Erythematosus raised patches with adherent keratotic scaling and
	follicular plugging; atrophic scarring may occur in older lesions
Photosensitivity	Skin rash as a result of unusual reaction to sunlight, by patient history
	or physician observation
Oral ulcers	Oral or nasopharyngeal ulceration, usually painless, observed by a
	physician
Arthritis	Nonerosive arthritis involving 2 or more peripheral joints,
	characterized by tenderness, swelling, or effusion
Serositis	Pleuritis - convincing history of pleuritic pain or rub heard by a
	physician or evidence of pleural effusion OR
	Pericarditis - documented by EKG, rub or evidence of pericardial
	effusion
Renal disorder	Persistent proteinuria greater than 0.5 grams per day or greater than 3+
	if quantitation not performed OR
	Cellular casts - may be red cell, hemoglobin, granular, tubular, or
	mixed
Neurologic	Seizures OR
disorder	psychosis - in the absence of offending drugs or known metabolic
	derangements (uremia, ketoacidosis, or electrolyte imbalance)
Hematologic	Hemolytic anemia - with reticulocytosis OR
disorder	Leukopenia - less than 4.000/mm3 total on two or more occasions OR
	Lymphopenia - less than 1.500/mm3 on two or more occasions OR
	Thrombocytopenia - less than 100.000/mm3 in the absence of
	offending drugs
Immunologic	Positive antiphospholipid antibody OR
disorders	Anti-DNA - antibody to native DNA in abnormal titer OR
	Anti-Sm - presence of antibody to Sm nuclear antigen OR
	False positive serologic test for syphilis known to be positive for at
	least six months and confirmed by Treponema pallidum
	immobilization or fluorescent treponemal antibody absorption test
Antinuclear	An abnormal titer of antinuclear antibody by immunofluorescence or
antibody	an equivalent assay at any point in time and in the absence of drugs
	known to be associated with "drug-induced lupus" syndrome

APPENDIX II SURVEY INVITATION LETTER





APPENDIX III SURVEY INSTRUMENT





1. Pl	ease enter the year you were diagnosed with Lupus:	<u> </u>
As yo Lupu relate	ou know, Lupus is an unpredictable disease with many diff is has a different experience. We would like to know about ed symptoms.	ferent symptoms. Everyone with t your experiences with Lupus-
Lup	us Flares	
2. V L	Ve'd like to know if you have had a lupus flare in the past upus gets worse. If you have had a flare, we'd like to know	<u>3 months</u> . A flare is when your w how severe it was.
Place	a check mark next to the response that <u>best fits</u> your expe	eriences.
	In the past 3 months , have you had a Lupus flare? A	□ No, no flare.
	Hare is when your Lupus gets worse. Which of these statements best describes you?	□ Yes, moderate flare
	when of these statements best describes you.	\Box Yes, severe flare.
3.	How would you describe your Lupus and Lupus sympt	oms <u>currently</u> ?
	Currently my Lupus and Lupus symptoms is/are:	□ Not Active/In Remission
		☐ Mildly Active
		□ Very Active



Section B:

Having Lupus may interfere with different areas of your life.

Circle the number that corresponds with how much Lupus and/or its treatments has interfered with each area of your life in the **past 3 months**.

1.	HEALTH	1	2	3	4	5	6	7
		Not Very Mu	ch					Very Much
2.	DIET (the things you eat and drink)	1	2	3	4	5	6	7
		Not Very Mu	ch					Very Much
3.	WORK	1	2	3	4	5	6	7
	□Not Applicable	Not Very Mu	ch					Very Much
4.	SCHOOL/EDUCATION	1	2	3	4	5	6	7
	□Not Applicable	Not Very Mu	ch	100	20			Vom March
		1	2	2	4	5	6	v ery Much
5.	HOUSEHOLD TASKS & CHORES	I NetVen Ma	-1-	3	4	3	0	1
		Not very Mu	cn					v ery Mucn
6.	ACTIVE RECREATION	1	2	3	4	5	6	7
	(e.g. sports, aerobics, swimming, etc.)	Not Very Mu	ch					Very Much
7.	PASSIVE RECREATION	1	2	3	4	5	6	7
	(e.g. reading, watching t.v., etc.)	Not Verv Mu	ch	2		2	U	Verv Much
		1	2	3	4	5	6	7
8.	FINANCES	Not Very Mu	ch					Very Much
9.	SPOUSE RELATIONSHIP	1	2	3	4	5	6	7
	(girlfriend/boyfriend/partner if not married)	Not Very N	1uch	5	7	2	U	Verv Much
	□Not Applicable	110170191	100000					, ,, , , ,, ,, ,, ,, ,, ,, ,, ,, ,, ,,
10	SEX LIFE	1	2	3	4	5	6	7
	⊔Not Applicable	Not Very Mu	ch					Very Much
11	FAMILY RELATIONSHIPS	1	2	3	4	5	6	7
		Not Very Mu	ch					Very Much
12	OTHED DELATIONSHIDS	1	2	3	4	5	6	7
12	OTHER RELATIONSHIPS	Not Very Mu	ch					Very Much
10	GELE EXADEGGION	1	2	3	4	5	6	7
15	SELF-EXPRESSION	Not Verv Mu	ch	5		5	0	Verv Much
		1	2	2	4	5	6	7
14	RELIGIOUS EXPRESSION	Not Very Mu	ch 2	3	4	5	0	Very Much
15	COMMUNITY INVOLVEMENT		2	3	4	5	6	7
		wot very Mu	cn					v ery Much
16	ENERGY OR VITALITY	1	2	3	4	5	6	7
		Not Very Mu	ch					Very Much

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Section C: Importance of Life Domains

Order the following areas of your life (or 'life domains') in terms of how important they are to you. Use each number only once.

For example, if maintaining a home is most important to you, you would write "1" in the ranking column beside "Housework/Maintaining a Home".

Life Domain	Ranking (1-5)
Work and/or School	
Work includes paid or unpaid employment. School could mean or academic (e.g. university) or training programs (e.g. apprenticeships)	
Finances	
Money, managing money, budgeting, etc.	
Marital and Family Relationships	
Spousal relationships (including husband/wife/boyfriend/girlfriend/partner) or relationships with family members, including children	
Other Social Relationships	
Relationships with people not related to you like friends and coworkers	
Housework/Maintaining a Home	
Housework and chores, household maintenance, etc.	

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Do Do				
Type of Support this	you need is kind of upport?	Are you receiving this kind of support (whether or not you need it)	Thinking about the amount of support others give you, are you receiving the right amount? (whether or not you need it)	
pport for activities g. help doing tasks, modified turs, change in exponsibilities)	No Ves	▲ □ No □ Yes	 ☐ I would like <u>more</u> support ▲ I am receiving <u>the right amount</u> of support ☐ I would like <u>less</u> support 	Go to Next Row
notional Support	No Yes	 ▲ □ No □ Yes 	 □ I would like <u>more</u> support ▶ □ I am receiving <u>the right amount</u> of support □ I would like <u>less</u> support 	Go to Next Row
viding information or vice □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □	No Ves	 ▲ □ No □ Yes 	 ☐ I would like <u>more</u> support ▲ I am receiving <u>the right amount</u> of support ☐ I would like <u>less</u> support 	→ Go to Question 2 on next page

	f support or not you need it)	I hinking about the amount of support others give you, are you receiving the right amount? (whether or not you need it)	
elp participating in family	No Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	→ Go to Next Row
motional Support .g. someone to listen to you)	No Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	Go to Next Row
oviding information or advice □ No → □ 1 <i>g. advice for your</i> □ Yes □ '	No Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	 Go to Question 3 on next page

Type of Support th	o you need his kind of support?	Are you receiving this kind of support (whether or not you need it)	Thinking about the amount of support others give you, are you receiving the right amount? (whether or not you need it)	
telp or support for ctivities e.g. access to travel, elp that gives you time o participate in ctivities, etc)	No Yes	◆ □ No □ Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	→ Go to next Row
inotional Support	No Yes	■ No□ Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	Go to Next Row
roviding information or dvice e.g. <i>information about</i> ccess to community rograms, etc)	No Yes	→ □ No □ Yes	 I would like <u>more</u> support I am receiving <u>the right amount</u> of support I would like <u>less</u> support 	Go to Question 4 on next page

MORRISON, S.E.



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ILIARC VUL	mprentig your more in eeded or received ir	athis area of your life in the par	t 3 months?	.ងាកវារ
)o you need this cind of support?	Are you receiving this kind of support (whether or not you need it)	Thinking about the amount of support others give you, are you receiving the right amount? (whether or not you need it)	
	□ No □ Yes	■ No □ Yes	 ☐ I would like <u>more</u> support ▶ ☐ I am receiving <u>the right amount</u> of support □ I would like <u>less</u> support 	Go to next Row
	 No Yes 	□ No	 ☐ I would like <u>more</u> support ▶ □ I am receiving <u>the right amount</u> of support □ I would like <u>less</u> support 	Go to Next Row
	□ No □ Yes	□ No Tes	 ☐ I would like <u>more</u> support ☐ I am receiving <u>the right amount</u> of support ☐ I would like <u>less</u> support 	Go to Next Question 6 on next page
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MORRISON, S.E.

Section E:

The following are some statements that a woman living with Lupus might make. Everyone thinks, acts and feels differently. None of the statements are "right" or "wrong", just different. We're interested in whether you agree or disagree that each of the following statements sounds like you.

Check the box that best describes how much you agree with each statement.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I do most things and make most decisions on my own.					
2. I feel like I am an independent person.					
3. My friends and family are overprotective of me because of my health.					
4. I don't get enough support from others to help me manage all my activities and take good care of my health.					
 When I need help, advice or information about Lupus, there isn't anyone in my personal life who can give it to me. 					
 I have a good balance of independence and support in my life. 					
7. I wish I could do more for myself.					
8. I often feel too dependent on others for support.					
9. I don't mind it when other people do things for me.					
 If I didn't have friends or family around to support me, I don't know what I would do. 					
11. Others sometimes step in and do things for me even when I say I don't need help.					
12. My health hasn't created the need for extra help and support in my life.					
13. I would like more support in my life.					

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0%	100%
You are about <u>h</u>	alfway through this questionnaire.
Thank you agai	n for completing this survey in full.
Please use the space belo you wou	w if there is anything about your experiences ld like to tell us at this point.
_	
Jersion 1: 22Mav14	Page 14 of

We would like to ask you a few questions about your social net people who are closest to you and the relationships you have w	twork. A social ne	etwork is the
1. How many <u>close friends</u> do you have?	🗆 None Go to	Question 3
A close friend is something that you feel at ease with, you		1
can talk to them about your private life and you might call on them for help when you need it	□ 2	
	□ 3 or 4	Go to
	□ 5 to 8	Question 2 below
	\Box 9 or more –	JUCIOW
2. How many of these friends do you see <u>at least</u>	🗆 None	
once a month?		
	□ 2	
	□ 3 or 4	
	□ 5 to 8	
	□ 9 or more	
3. Thinking of your <u>closest friend</u> , how often do you see or	🗆 less than mo	onthly
hear from that person?	\Box monthly	
	\square a few times a	a month
	□ weekly	
	\Box a few times a	a week
	🗆 daily	
4. How many <u>close relatives</u> do you have?	🗆 None Got	o Question 8 on
	next	page
		Go to
		Question 5
	\Box 3 or 4	- 501011
	□ 9 or more	
5. How many of these relatives do you see <u>at least once a</u> month?		
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5. Thinking of your <u>closest relative</u> , how often do you see or	□ less than monthly
hear from that person?	□ monthly
	□ a few times a month
	□ weekly
	□ a few times a week
	🗆 daily
7. When you have an important decision to make do you have someone you can talk to about it?	🗆 Never
someone you can tark to about H?	□ Seldom
	□ Sometimes
	🗆 Often
	🗆 Very Often
	🗆 Always
2. When other people you know have an important decision to	□ Never
	□ Seldom
	Sometimes
	🗆 Often
	🗆 Very Often
	🗆 Always
9.a) Does anybody <u>rely on you</u> to something for them each dav?	Yes Go to Question 9b
	□ No Go to Question 10
9.b) Do you help anybody with something each day?	🗆 Very Often
	🗆 Often
	Sometimes
	□ Seldom
	🗆 Never
10. Do you live alone or with relatives?	\Box Live with spouse
	□ Live with other relatives or friends
	□ Live with other unrelated individuals (e.g. roomates, paid help)
	□ Live Alone

Section G: Your Social Network continued

Now we'd like to know how much support you have from your family and friends -- your social network.

We would like you to tell us how often you are able to rely on members of your social network for different things you may need.

How socia	often can you rely on someone in your I network for:	None of the time	Little of the time	Some of the time	Most of the time	All of the time
1.	Someone you can count on to listen to you when you need to talk.					
2.	Someone who shows you love and affection.					
3.	Someone to give you information to help you understand a situation.					
4.	Someone whose advice you really want.					
5.	Someone to help with daily chores if you were sick.					
6.	Someone to share your most private worries and fears.					
7.	Someone to do something enjoyable with.					

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Section H:

Everyone feels upset or down sometimes. Sometimes these feelings are more severe and last longer, and we feel depressed.

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the **<u>past week**</u>.

We would like you to tell us how often you have felt a particular way by circling the response that sounds the *most* like you.

During the past week :	Rarely or None of the Time (0-1 days)	Some or a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of Time (3-4 days)	Most or All of the Time (5-7 days)
 I did not feel like eating; my appetite was poor. 				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family or friends.				
 I felt that I was just as good as oth people. 	ler 🗌			
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failu	re.			
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
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During the past week :	Rarely or None of the Time (0-1 days)	Some or a Little of the Time (1-2 days)	Occasionally or a Moderate Amount of Time (3-4 days)	Most or All of the Time (5-7 days)
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people dislike me.				
20. I could not get "going".				

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Section I:

Living with Lupus sometimes means different things to different people. We would like to know what having Lupus means in your life.

The following questions ask how you see life to be affected by Lupus.

Check the box that best describes how you have been feeling during the past 2 weeks .	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I feel that Lupus is something I will never recover from.				
2. I feel that Lupus is serious, but I will be able to return to life as it was before.				
3. I feel that Lupus is changing my life permanently so they will never be as good again.				
 I feel I am making a complete recovery from my Lupus symptoms. 				
5. I feel that I am the same person I was before I was diagnosed with Lupus.				
 I feel my relationships with others have not been negatively affected by me having Lupus. 				
7. I feel Lupus has permanently interfered with my ability to achieve the most important goals I have set for myself.				
8. I feel my experience with Lupus has made me a better person.				
9. The uncertainty of Lupus is causing me great difficulty.				

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Section J: Life Satisfaction

Below are five statements that you may agree or disagree with when thinking about your own life.

Check the box that best describes how strongly you agree or disagree with each statement. There are no right or wrong answers, and we urge you to be open and honest with how you feel.

	Strongly Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Strongly Agree
1. In most ways, my life is close to ideal.							
2. The conditions of my life are excellent.							
3. I am satisfied with my life.							
4. So far, I have gotten the important things I want in life.							
 If I could live my life over, I would change almost nothing. 							

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Section K: Demographic Information

Questions on gender, marital status, education, and insurance are standard information collected in many types of surveys to help us describe the respondents to our surveys.

We would like to remind you that all information collected in this form is **<u>confidential</u>**. You have the right not to answer any of these questions; however all of them are valuable to us.

Age – How old are you today?	
Marital Status	□ Single (never married)
	□ Married / Living as married
	□ Widowed
	□ Separated
	Divorced
Total Annual Household Income	Less than \$30,000
include all sources, including	□ \$30,000 - \$50,000
investments pensions welfare	□ \$50,001 - \$70,000
disability etc	□ \$70,001 - \$100,000
	□ More than \$100,000
Education	Less than High School
1	□ High School diploma/GED
approximate a second se	□ Some college/university, but no completed degree
compreteu	Undergraduate University degree or College diploma
	Some graduate school or professional training
	Graduate or Professional Degree
Work Status	□ Full-time worker
Please choose the work status that	□ Part-time worker
best fits your situation.	□ On sick leave, leave of absence or short-term disability
If you are working and going to	□ On long-term disability
school, please check "Student" and	□ Not working outside the home, but looking for work
time worker.	□ Not working outside the home, <u>not</u> looking for work
	Retired
	□ Student

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Thank you very much for providing us with this va	luable information.
Please mail this questionnaire back to us using the	stamped envelope provided.
Please use the space below if there is anything else about your experiences.	you would like to tell us
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APPENDIX IV REMINDER LETTER

UHN	UNIVERSITY OF TORONTO
August 7, 2014	
RE: Understanding the Support	t Needs and Experiences of Women with Lupus
Dear Participant of the University	of Toronto Lupus Clinic Registry,
About a week ago [four weeks age experiences of women living with whether you would like more or le independence and dependence on	o] we contacted you about a study we're conducting on the lupus, especially about whether you feel well supported; ess support in your life; and your perceptions of your others.
If you have already completed the	questionnaire, please accept our thanks.
If you have not yet completed the this research. The questionnaire takes about 15- versions. The online questionnaire Please use invitation code:	questionnaire, we hope that you will be able to help us with 25 minutes to complete. It is available in both online and paper e can be found at <u>http://tinyurl.com/IndependenceInSLE</u> .
If you would prefer to complete th	ne questionnaire in paper form, simply call us to request a copy.
We very much appreciate your he all of the information you provide	lp with this research study. We would like to assure you that will be kept confidential.
If you have any questions about the please contact Stacey Morrison at telephone number for collect long	ne questionnaire or you didn't receive our earlier invitation, , 416-603-5800, extension 2361. Please feel free to use this -distance calls from your location.
Thank you very much for conside you.	ring this research study, and we look forward to hearing from
Respectfully,	
Stacey Morrison Candidate for MSc, Institute of Health Po	olicy, Management and Evaluation, University of Toronto

APPENDIX V Research Ethics Board Approvals

V.1 University Health Network Research Ethics Board Approval

University Health Network Research Ethics Board Toronto Western Princess Margaret 10th Floor, Room 1056 700 University Ave Toronto, Ontario, M5G 1Z5 Phone: (416) 581-7849 Notification of REB Initial Approval Date: August 11th, 2014 To: Dr. Monique Gignac Room 10 MP-328, 10th Floor, Main Pavilion, Toronto Western Hospital, 399 Bathurst St. 14-7492-AE Re: Agreement or Discordance Between Need and Receipt of Social Support and Perceptions of Independence and Well-Being in Women with Systemic Lupus Erythematosus (SLE) **REB** Review Type: Expedited REB Initial Approval Date: August 11th, 2014 **REB** Expiry Date: August 11th, 2015 Documents Approved: Protocol Version date: July 4th, 2014 Reminder Letter Version date: July 4th, 2014 Introduction Letter Version date: August 6th, 2014 Participant Questionnaire (Web-based) Version date: July 4th, 2014 Participant Questionnaire (Paper Based) Version date: August 6th, 2014 The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement; ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada. The approval and the views of the REB have been documented in writing. Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. Best wishes on the successful completion of your project. Sincerely, ann Alan Barolet, MD PhD FRCPC Co-Chair, University Health Network Research Ethics Board Page 1 of 1

V.2 University Health Network Research Ethics Board Amendment

2	UFFIN Toronto General Toronto Western Princess Margaret Toronto Rehab		University Health Network Research Ethics Board 10th Floor, Room 1056 700 University Ave Toronto, Ontario, M5G 125 Phone: (416) 581-7849
	Not	fication of REB Amendment Approval	1 1010. (+10) 301-7043
Date: To:	August 6th, 2015 Dr. Monique Gignac Room 10 MP-328, 10th Floor,	Main Pavilion, Toronto Western Hospital, 399) Bathurst St.
Re:	14-7492-AE Agreement or Discordance Be Independence and Well-Being	tween Need and Receipt of Social Support ar	nd Perceptions of
	independence and weil-being	in women with systemic Lupus Erythematos	us (SLE)
REB R REB Ir REB A REB E	teview Type: nitial Approval Date: .mendment Approval Date: xpiry Date:	Expedited August 11th, 2014 August 6th, 2015 August 11th, 2015	
Docun Prote	nents Approved: ocol	Version date: July 9th, 201	5
or the F Regula Best wi Sincere Leda Iv	ood and Drug Regulations; Part tions of Health Canada. The app shes for the successful completi ly, tic Weiss, MSc	4 of the Natural Health Products Regulations proval and the views of the REB have been do on of your project.	and the Medical Devices
Resear <i>For</i> : Ala Co-Cha	ch Ethics Coordinator n Barolet, MD PhD FRCPC ir, University Health Network Re	search Ethics Board	
			Page 1 of 1

V.3 University Health Network Annual Approval

	UFRN Toront Toront Princes Toronte	o General Western Margaret Rehab			University Health Network Research Ethics Board 10th Floor, Room 1056 700 University Ave Toronto, Ontario, M5G 125
		Notification of F	REB Continued App	roval	Phone: (416) 581-7849
Date:	August 6th, 2015				
Го:	Dr. Monique Gignac Room 10 MP-328, 10th	Floor, Main Pavilion	, Toronto Western He	ospital, 399	Bathurst St.
Re:	14-7492-AE Agreement or Discorda Independence and We	nce Between Need a Il-Being in Women wi	and Receipt of Social ith Systemic Lupus E	Support and rythematosu	d Perceptions of us (SLE)
REB R REB Ir REB A REB E	eview Type: nitial Approval Date: nnual Approval Date: xpiry Date:	Expedited August 11th August 11th August 11th	n, 2014 n, 2015 n, 2016		
or Goo	d Clinical Practice E6(R	1); Ontario Personal	Health Information P	rotection Ac	t (2004); Part C Division 5
or Goc of the F Regula Best wi Sincere Leda Iv Resear	vic Weiss, MSc roch Ethics Coordinator	a operates in compi 1); Ontario Personal ns; Part 4 of the Natu The approval and the completion of your pr	Health Information P ural Health Products a views of the REB ha	rotection Ac Regulations ave been do	t (2004); Part C Division 5 and the Medical Devices cumented in writing.
or Goc of the F Regula Best wi Sincere Leda Iv Resear For: Ala Co-Cha	A Clinical Practice E6(R Food and Drug Regulation tions of Health Canada. shes on the successful of the weiss, MSc ric Weiss, MSc rich Ethics Coordinator an Barolet, MD PhD FRC air, University Health Ne	T); Ontario Personal ns; Part 4 of the Natu The approval and the completion of your pro- completion of	Health Information P ural Health Products a views of the REB ha oject.	rotection Ac Regulations ave been do	t (2004); Part C Division 5 and the Medical Devices ocumented in writing.
or Goc of the F Regula Best wi Sincere Ceda Iv Resear For: Ala	A Clinical Practice E6(R Food and Drug Regulation tions of Health Canada. shes on the successful of the Weiss, MSc ric Weiss, MSc ric Hethics Coordinator an Barolet, MD PhD FRC air, University Health Ne	2); Ontario Personal ns; Part 4 of the Natu The approval and the completion of your pro- CPC work Research Ethic	Health Information P ural Health Products a views of the REB ha oject.	rotection Ac Regulations ave been do	t (2004); Part C Division 5 and the Medical Devices ocumented in writing.
or Goc of the F Regula Best wi Sincere Leda Iv Resear For: Ala	Arrestation Ethos Bod od Clinical Practice E6(R Food and Drug Regulation tions of Health Canada. shes on the successful why whic Weiss, MSc roch Ethics Coordinator an Barolet, MD PhD FRG air, University Health Ne	CPC work Research Ethic	Health Information P ural Health Products a views of the REB ha oject.	rotection Ac Regulations ave been do	t (2004); Part C Division 5 and the Medical Devices accumented in writing.
V.4 University of Toronto Ethics Review Board Approval

UNIVERSITY OF OFFICE OF THE VICE-PRESIDENT, RESEARCH AND INNOVATION TORONTO PROTOCOL REFERENCE # 30642 August 21, 2014 Dr. Dorcas Beaton Ms. Stacey E. Morrison INST OF HEALTH POLICY, MANAGEMENT & INST OF HEALTH POLICY, MANAGEMENT & **EVALUATION EVALUATION** DALLA LANA SCHOOL OF PUBLIC HEALTH DALLA LANA SCHOOL OF PUBLIC HEALTH Dear Dr. Beaton and Ms. Stacey E. Morrison, Re: Administrative Approval of your research protocol entitled, "Agreement or discordance between need and receipt of social support and perceptions of independence and well-being in women with Systemic Lupus Erythematosus (SLE)" We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital: Graduate Student research - hospital-based only Storage or analysis of De-identified Personal Information (data) This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review. Best wishes for the successful completion of your research. Yours sincerely, Dario Kuzmanovic **REB** Manager OFFICE OF RESEARCH ETHICS McMurrich Building, 12 Queen's Park Crescent West, 2nd Floor, Toronto, ON M5S 1S8 Canada Tel: +1 416 946-3273 • Fax: +1 416 946-5763 • ethics.review@utoronto.ca • http://www.research.utoronto.ca/for-researchers-administrators/ethics/

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				Respo	inse:			
	Variahla		$0 = \mathbf{R}_{i}$	rely or	none o	of the	Mean (std	Item to Total
Item	Label	Missing	time,	3 = Mo the t	ost or a ime	ll of	dev) [0 – 3 scale]	Score correlation
			•	-	5	6		
I was bothered by things that usually don't bother me.	CESD1	10	101	24	20	2	0.53 (0.85)	0.53
I did not feel like eating: my appetite was poor.	CESD2	10	79	42	24	5	0.70 (0.86)	0.61
I felt that I could not shake off the blues even with help from my family or friends.	CESD3	11	84	35	21	6	0.70 (0.93)	0.75
I felt that I was just as good as other people.	CESD4	11	69	38	30	12	(66.0) 06.0	0.57
I had trouble keeping my mind on what I was doing.	CESD5	10	44	55	36	15	1.15 (0.96)	0.54
I felt depressed.	CESD6	10	81	48	15	9	0.64 (0.82)	0.78
I felt that everything I did was an effort.	CESD7	10	48	62	40	0	0.95 (0.77)	0.71
I felt hopeful about the future.	CESD8	10	55	43	42	10	1.05 (0.96)	0.49
I thought my life had been a failure.	CESD9	10	102	30	12	9	0.48 (0.81)	0.61
I felt fearful.	CESD10	10	81	45	20	4	0.65 (0.81)	0.72
My sleep was restless.	CESD11	11	29	56	29	35	0.65 (0.81)	0.57
I was happy.	CESD12	10	61	61	20	8	0.83 (0.85)	0.74
I talked less than usual.	CESD13	12	62	49	32	5	0.86 (0.87)	0.61
I felt lonely.	CESD14	12	69	42	25	12	0.86 (0.97)	0.66
People were unfriendly.	CESD15	12	116	23	8	1	0.28 (0.59)	0.45
I enjoyed life.	CESD16	6	74	49	23	5	0.73 (0.84)	0.71
I had crying spells.	CESD17	10	98	36	14	2	0.47 (0.72)	0.69
I felt sad.	CESD18	10	68	52	24	6	0.79 (0.86)	0.78
I felt that people dislike me.	CESD19	11	121	12	14	2	0.31 (0.70)	0.53
I could not get "going".	CESD20	11	53	60	26	10	0.95 (0.90)	0.67
		CESD Scor	و					
		$\alpha = 0.93$						

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Center for Epidemiologic Studies Depression (CESD) Scale

STUDY SCALE ITEM-LEVEL ANALYSIS APPENDIX VI

VI.1

(0 - 60 scale, higher score = more depressive symptoms) mean (standard deviation) = 15.3 (10.9)

complete n = 148, missing n = 12

	VLL_				N N	sponse				Mean (std	Item to Total
Item	V ariable	Missing]=	Strong	ly disag	sree, 7	= Stron	igly agi	ree	dev)	Score
	Label		1	2	3	4	5	6	7	[1 – 7 scale]	Correlation
1. In most ways, my life is close to ideal.	SAT1	11	12	22	17	13	25	45	15	4.42 (1.89)	0.89
2. The conditions of my life are excellent.	SAT2	11	9	33	18	12	21	48	11	4.32 (1.84)	0.86
3. I am satisfied with my life.	SAT3	11	3	21	16	12	25	57	15	4.79 (1.69)	0.87
4. So far, I have gotten the important things I want in life.	SAT4	10	9	17	6	11	21	60	26	5.05 (1.76)	0.81
If I could live my life over, I would change almost nothing.	SAT5	11	6	29	20	11	19	45	16	4.35 (1.91)	0.72
	mean	SW (standard	VLS Sco α = 0.93 I deviati	ore (on) = 2	2.9 (7.1						
	(0 - 35 scal co	le, higher s mplete n =	core = 1 = 149, m	more lif issing n	ie satisf 1 = 11	action)					

VI.2 Satisfaction with Life Scale (SWLS)

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Item	Variable Label	Missing]=]	Difficu	lt all (Resp of the of the	onse: time, time	5=Dif	ficult	none	Mean (std dev)	Item to Domain	Domain to Index Score
			I	2	3	4	5	9	7	N/A	T-/ scale	correlation	COLLEIAUOI
Relationships & Personal Development Domain α = 0.85	IIRSsubrelat	15									2.24 (1.28)		0.93
Family	IIRSfamily	6	84	31	Ξ	6	Ξ	9	2	N/A	2.08 (1.57)	0.82	
Other Social Relationships	IIRSotherrel	7	80	28	13	12	~	~	4	N/A	2.22 (1.69)	0.85	
Self-Expression/Self-Improvement	IIRSself	7	30	24	24	16	12	25	22	N/A	3.78 (2.13)	0.78	
Religious Expression	IIRSreligion	5	77	10	6	-	5	e	-	49	1.15 (1.38)	0.63	
Community Involvement	IIRScommunity	9	77	17	16	15	6	12	5	N/A	2.46 (1.86)	0.80	
Passive Recreation	IIRSpassrec	6	66	27	12	5	8	1	2	N/A	1.75 (1.30)	0.71	
Intimacy Domain $\alpha = 0.77$	IIRSsubintimat	9									1.70 (1.80)		0.50
Spouse Relationship	IIRSspouse	5	61	20	6	4	8	7	e	43	1.59 (1.79)	0.88	
Sex Life	IIRSsex	9	44	16	10	9	9	7	11	54	1.81 (2.18)	0.92	
Instrumental Domain $\alpha = 0.86$	IIRSsubinst	18									2.41 (1.41)		0.94
Health	IIRShealth	6	52	21	25	10	11	22	13	N/A	3.16 (2.12)	0.85	
Diet	IIRSdiet	4	82	21	12	~	17	5	11	N/A	2.46 (1.97)	0.73	
Energy	IIRSenergy	10	76	23	19	10	10	5	7	N/A	2.32 (1.77)	0.79	
Household Maintenance	IIRShouse	6	53	17	16	20	21	20	7	N/A	3.18 (2.01)	0.82	
Work	IIRSwork	4	43	16	11	1	5	9	12	62	1.65 (2.17)	0.64	
School	IIRSschool	4	24	7	4	0	0	0	e	118	0.46 (1.14)	0.39	
Finances	IIRSfinance	9	82	20	18	9	4	7	14	N/A	2.38 (2.00)	0.72	
Active Recreation	IIRSactrec	6	50	15	15	21	17	15	21	N/A	3.45 (2.21)	0.77	
				ts Ind	ex Sc	ore	ĺ						
) = 0 	16.0		17 23	6					
	(0-7 scale	, higher sc	ore = 1	more	Intrus	ion of	illnes	s into	doma	(iii			
		201	anardu	CI-II	0, IIIIS	sing n	+						

VI.3 Illness Intrusiveness Rating Scale (IIRS)

MORRISON, S.E.

MASTERS THESIS

VI.4 Meaning of Illness (MOI)

				Respo	nse:		Moan (etd	Itam to Total	
Item	Variable Label	Missing	$\mathbf{I} = \mathbf{St}$	congly (trongly	disagre y agree	e, 4 =	dev)	Score	
			1	2	3	4	[I – 4 scale]	Correlation	
1. I feel that Lupus is something I will never recover from.	MOI1	15	27	66	38	15	2.28 (0.88)	0.65	
I feel that Lupus is serious, but I will be able to return to life as it was before.	MOI2	17	8	52	61	25	2.71 (0.82)	0.69	
I feel that Lupus is changing my life permanently so they will never be as good again.	MOI3	18	18	50	52	26	2.59 (0.92)	0.70	
 I feel I am making a complete recovery from my Lupus symptoms. 	MOI4	17	22	59	43	22	2.45 (0.92)	0.75	
5. I feel that I am the same person I was before I was diagnosed with Lupus.	MOI5	16	27	70	32	17	2.27 (0.90)	0.60	
I feel my relationships with others have not been negatively affected by me having Lupus.	MOI6	15	8	42	62	34	2.84 (0.85)	0.57	
7. I feel Lupus has permanently interfered with my ability to achieve the most important goals I have set for myself.	MOI7	16	12	49	63	22	2.65 (0.84)	0.65	
8. I feel my experience with Lupus has made me a better person.	MOI8	19	13	34	71	28	2.78 (0.86)	0.45	
 The uncertainty of Lupus is causing me great difficulty. 	MOI9	16	14	46	60	26	2.67 (0.88)	0.64	
	IOM	Scale Scor 1 = 0.63	a						
mear (9 - 36 scale, hig	(standard d her score = l	leviation) = upus has g	= 23.23 reater p	(4.99) ositive	meani	lg)			
complete (≤3 missing i	items) n =]	[46, mis	sing n	= 17	ì			

APPENDIX VII SCALE SCORING AND IMPUTATION RULES

Independence and Discordance

Figure 1 describes the independence and discordance groups resulting from responses to receipt and evaluation of support questions. Those with missing data for receipt or evaluation of support were excluded from analysis that included independence group or discordance only in the domain(s) and/or support type(s) that had missing data.

Center for Epidemiologic Studies Depression Scale (CESD)

Total scores were created by reversing the Likert-type scale for items 4, 8, 12 and 16 and summing across all 20 items. It has been reported that scales with more than 4 missing values are invalid (Hann *et al.*, 1999). In scales with 4 or fewer missing values, the individual mean of the remaining item replaced the missing items. Scales with more than 4 missing values were excluded from analysis.

Satisfaction with Life Scale (SWLS)

Total scale scores were created by summing across all 5 scale items. Given that the SWLS contains only 5 items, no imputation of missing values was used and any scales with missing items were excluded from analysis.

Illness Intrusiveness Rating Scale (IIRS)

Total IIRS scores were created by summing across all applicable items and dividing by the number of applicable items. It has been reported in previous studies that the IIRS developer, Dr. Devins, allows for 3 scale items to be missing before the scale is invalid. Since the index score is an average of item responses, for those with 3 or fewer missing items the denominator is reduced by the number of missing items. Data that is missing more than 3 items were excluded from analysis.

Constructed Meaning of Illness (MOI)

Dr. Fife, the author of the scale, described in personal communication that in sample sizes larger than 100 participants, 3 responses could be missing and leave the scale still valid. For those with 3 or fewer missing responses, the mean of the non-missing scale items replaces the missing items. Scales with more than 3 missing items were excluded from analysis.

Demographic, Clinical and Social Network Variables

Disease duration was calculated as the difference between the year of diagnosis and the year the survey was completed. VAS scales were measured in mm and converted to values between 0 and 10, to 1 decimal place. All other demographic and clinical variables were used as stated. Lubben Social Network Scale (LSNS) and MOS Social Support Scale (SSS) scores were calculated by summing across all items in each respective scale. Missing demographic, clinical and social network variables could not be imputed and were excluded from analysis.

APPENDIX VIII ASSESSMENT OF COLLINEARITY – MULTINOMIAL LOGISTIC REGRESSION OF DEMOGRAPHIC, CLINICAL AND SOCIAL NETWORK VARIABLES

	Age	Marital Status	Education	Household Income	Work Status	Disease Duration	Flares	Current Activity	Activity past 3 months	Fatigue	Pain	Activity since Diagnosis	MOS Social Support	Lubben Social Network
Age	1	0.50	-0.23	-0.02	0.53	0.65	60:0	0.12	0.23	0.05	0.36	-0.03	0.06	-0.06
Marital Status	0.50	1	-0.22	0.07	0.12	0.27	0.13	0.12	0.12	0.11	0.27	0.07	0.07	60.0
Education	-0.23	-0.22	1	0.26	-0.21	-0.24	-0.12	-0.21	-0.14	-0.14	-0.21	-0.07	-0.11	-0.12
Household Income	-0.02	0.07	0.26	1	-0.26	0.04	-0.04	-0.12	-0.16	-0.21	-0.13	-0.06	0.31	0.36
Work Status	0.53	0.12	-0.21	-0.26	1	0.29	0.08	0.19	0.31	0.21	0.32	0.02	-0.07	-0.08
Disease Duration	0.65	0.27	-0.24	0.04	0.29	1	-0.11	0.01	0.07	0.01	0.22	0.04	0.21	0.07
Flares	0.09	0.13	-0.12	-0.04	0.08	-0.11	1	0.61	0.58	0.38	0.43	0.23	-0.12	-0.08
Current Activity	0.12	0.12	-0.21	-0.12	0.19	0.01	0.61	1	0.68	0.43	0.55	0.28	-0.10	-0.03
Activity past 3 months	0.23	0.12	-0.14	-0.16	0.31	0.07	0.58	0.68	1	0.65	0.70	0.33	-0.06	-0.06
Fatigue	0.05	0.11	-0.14	-0.21	0.21	0.01	0.38	0.43	0.65	1	0.62	0.32	-0.21	-0.12
Pain	0.36	0.27	-0.21	-0.13	0.32	0.22	0.43	0.55	0.70	0.62	1	0.37	-0.21	-0.12
Activity since Diagnosis	-0.03	0.07	-0.07	-0.06	0.02	0.04	0.23	0.28	0.33	0.32	0.37	1	0.02	-0.03
MOS Social Support	0.06	0.07	-0.11	0.31	-0.07	0.21	-0.12	-0.10	-0.06	-0.21	-0.07	0.02	1	0.56
Lubben Social Network	-0.04	0.09	-0.12	0.36	-0.08	0.07	-0.08	-0.03	-0.06	-0.12	-0.06	-0.03	0.56	1

APPENDIX IX ADDITIONAL RESULTS

IX.i Prioritizing Life Domains

Table 19 describes which life domains were ranked highest (ranked "1") and lowest

(ranked "5).

Table 19.	Prioritizing life domains , n = 128
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Domain	Ranked Domain Highest n (%)	Ranked Domain Lowest n (%)
Employment & Education	11 (8.8%)	43 (34.4%)
Recreation & Social Activities	4 (3.2%)	36 (28.6%)
Personal Finances	9 (7.0%)	9 (7.0%)
Family Relationships	96 (75.6%)	7 (5.5%)
Household Maintenance	6 (4.8%)	32 (25.6%)



Figure 10. Distribution of life domain priority rankings

IX.ii Independence Groups and Well-Being Outcomes

Tables 20 and 21 compare the mean well-being scores between groups for each support

type in the personal finances and household maintenance domains, respectively.

Table 20.Outcome scores by independence group & support type, Personal
Finances domain, n = 128

	I	ndependence Grou (outcome mean ± SD)	p	Between	Group Comp	arisons [‡]
Outcome Type of Support	Conco	ordant	Discordant		FF	
	Independent	Dependent	Not Independent/ Under-Supported	IN vs DE	IN vs US	DE vs US
CESD						
Instrumental	15.10 ± 10.79	14.40 ± 10.76	21.67 ± 11.04	NS	NS	NS
[†] Emotional	12.67 ± 7.64	13.60 ± 10.34	18.96 ± 7.12	NS	***	***
[†] Informational	13.76 ± 10.46	10.54 ± 8.77	22.98 ± 10.12	NS	***	***
SWLS						
[†] Instrumental	23.84 ± 8.06	22.83 ± 6.06	17.86 ± 6.59	NS	***	NS
[†] Emotional	24.11 ± 7.64	23.64 ± 7.07	18.96 ± 7.12	NS	***	***
[†] Informational	24.00 ± 7.48	24.53 ± 7.16	19.87 ± 7.12	NS	***	***
IIRS						
[†] Instrumental	2.21 ± 1.29	3.07 ± 1.48	3.28 ± 1.37	***	***	NS
[†] Emotional	2.09 ± 1.22	2.69 ± 1.42	3.56 ± 1.31	NS	***	***
[†] Informational	2.13 ± 2.18	2.54 ± 1.30	3.26 ± 1.46	NS	***	***
MOI						
Instrumental	23.79 ± 5.44	22.50 ± 4.13	21.50 ± 4.43	NS	NS	NS
Emotional	24.24 ± 5.19	23.36 ± 4.45	20.71 ± 4.02	NS	***	NS
[†] Informational	24.31 ± 5.31	23.97 ± 4.48	20.80 ± 4.16	NS	***	NS

Notes: SD = standard deviation

 \dagger pre hoc F-test across all three groups significant at p < 0.05

‡ IN = Independent; DE = Dependent; US = Not Independent/Under-Supported

*** Difference in means significant at p < 0.05

	Iı	ndependence Grou (outcome mean ± SD)	p	Between	Group Comp	arisons‡
Type of Support	Conco	rdant	Discordant		1 1	
	Independent	Dependent	Not Independent/ Under-Supported	IN vs DE	IN vs US	DE vs US
CESD						
[†] Instrumental	12.06 ± 11.15	14.15 ± 10.32	20.59 ± 10.72	NS	***	***
[†] Emotional	12.49 ± 9.78	12.95 ± 6.74	23.92 ± 10.70	NS	***	***
[†] Informational	12.74 ± 9.76	12.43 ± 9.88	22.46 ± 10.76	NS	***	***
SWLS						
[†] Instrumental	25.32 ± 7.79	23.93 ± 6.57	19.74 ± 6.68	NS	***	***
[†] Emotional	24.61 ± 7.40	24.25 ± 6.74	19.09 ± 7.08	NS	***	***
[†] Informational	24.63 ± 7.45	24.12 ± 6.46	19.85 ± 7.12	NS	***	***
IIRS						
[†] Instrumental	1.58 ± 0.75	2.91 ± 1.46	3.14 ± 1.41	***	***	NS
[†] Emotional	1.76 ± 0.89	2.81 ± 1.47	3.27 ± 1.44	***	***	NS
[†] Informational	1.83 ± 0.97	3.02 ± 1.46	3.21 ± 1.48	***	***	NS
MOI						
[†] Instrumental	26.68 ± 5.26	23.12 ± 6.57	19.74 ± 6.68	***	***	NS
[†] Emotional	24.87 ± 4.96	23.82 ± 4.30	19.51 ± 3.88	NS	***	NS
[†] Informational	25.30 ± 5.08	23.70 ± 3.60	20.03 ± 4.22	***	***	NS

Table 21.Outcome scores by independence group & support type, Household
Maintenance domain, n = 135

Notes: SD = standard deviation

† pre hoc F-test across all three groups significant at p < 0.05

‡ IN = Independent; DE = Dependent; US = Not Independent/Under-Supported

*** Difference in means significant at p < 0.05

IX.iii Factors Associated with Independence Group

The final models, which include variables associated with independence group (p < 0.2

on the Wald test) for the finance and household maintenance domains are presented in

Tables 22 and 24, respectively. Tables 23 and 25 show the associations (odds ratios and

95% confidence intervals) between each variable in the final models and independence

group in the finances and household maintenance domains, respectively.

Table 22.Final multinomial logistic regression models: Demographic, clinical & social network variables associated with
Independence group (p<0.2 on the Wald test) – Finances domain, n = 120</th>

Variable	Instrumental S	Support	Emotional Su	pport	Emotional Sur	oport
variable	Wald Chi Square	p-value	Wald Chi Square	p-value	Wald Chi Square	p-value
Demographic Characteristics						
Age, Years	8.17	0.017			7.78	0.021
Married					6.46	0.040
≥High School					4.96	0.084
Annual Household Income ≥ \$70K						
Involuntarily out of Work	7.45	0.024			9.42	0.009
Clinical Characteristics	0		0		0	
Disease Duration, Years						
No Flare past 3 months			12.53	0.002	5.85	0.054
Current Remission						
Activity past 3 months, 10-pt VAS			5.24	0.073		
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS	8.82	0.012	10.09	0.007	6.18	0.046
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics	0		0		n	
MOS Social Support Scale, Higher scores = more support	13.51	0.001	20.22	< 0.0001	11.38	0.003
Lubben Social Network Scale, higher scores = larger/tighter networks						

Table 23.Multinomial logistic regression models (variables significant overall at p < 0.05): Association (odds ratios and
95% confidence intervals) between demographic, clinical and social network variables and Independence group
– Finances domain, n =120

Variable	Instrumen	tal Support	Emotiona	l Support	Information	nal Support
variable	IN vs DE	IN vs US	IN vs DE	IN vs US	IN vs DE	IN vs US
Demographic Characteristics						
Age, Years	1.04‡ (1.01 – 1.07)					
Married					5.07† (1.44 – 17.85)	
≥High School						$0.26^{\dagger}_{(0.07-0.94)}$
Annual Household Income ≥ \$70K						
Involuntarily out of Work	0.30^{\dagger} (0.11 – 0.84)					8.86‡ (2.19 – 35.94)
Clinical Characteristics						
Disease Duration, Years						
No Flare past 3 months			12.28 ‡ (3.06 – 49.26)	5.36† (1.13 – 25.49)	3.47† (1.06 − 11.36)	3.84† (1.16–12.77)
Current Remission						
Activity past 3 months, 10-pt VAS			0.73† (0.55 – 0.96)			
Pain past 3 months, 10-pt VAS						
Fatigue past 3 months, 10-pt VAS	1.19† (1.02 – 1.39)	1.29† (1.04 – 1.60)	1.29† (1.05 – 1.58)	1.42 ‡ (1.12 – 1.79)		1.26† (1.04 – 1.52)
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics						
MOS Social Support Scale, higher scores = more support available		0.85; (0.76 – 0.95)	1.17‡ (1.06 – 1.29)		1.20 ‡ (1.07 – 1.34)	
Lubben Social Network Scale, higher scores = larger/tighter networks						

IN: Independent, DE: Dependent, US: Not Independent/Under-Supported

Pr > Chi Square: †p<0.05; ‡p<0.01

V	Instrumental S	Support	Emotional Su	pport	Emotional Sur	oport
variable	Wald Chi Square	p-value	Wald Chi Square	p-value	Wald Chi Square	p-value
Demographic Characteristics						
Age, Years	3.78	0.151	5.48	0.065	4.77	0.092
Married			6.53	0.038		
≥High School	4.71	0.095			4.07	0.131
Annual Household Income ≥ \$70K			3.38	0.184	5.88	0.053
Involuntarily out of Work	4.08	1.30				
Clinical Characteristics	0		и И		0	
Disease Duration, Years						
No Flare past 3 months					4.50	0.106
Current Remission						
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS	6.91	0.032				
Fatigue past 3 months, 10-pt VAS	5.71	0.058	14.14	0.001	9.38	0.009
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics						
MOS Social Support Scale, Higher scores = more support	12.65	0.002	19.50	<0.0001	9.29	0.010
Lubben Social Network Scale, higher scores = larger/tighter networks	3.46	1.177				

Table 24.Final multinomial logistic regression models: Demographic, clinical & social network variables associated withIndependence group (p<0.2 on the Wald test) – Household Maintenance domain, n = 126

Table 25. Multinomial logistic regression models (variables significant overall at p < 0.05): Association (odds ratios and 95% confidence intervals) between demographic, clinical and social network variables and Independence group - Household Maintenance domain, n = 120

Variable	Instrumental Support		Emotional Support		Informational Support	
	IN vs DE	IN vs US	IN vs DE	IN vs US	IN vs DE	IN vs US
Demographic Characteristics						
Age, Years			1.04† (1.00 – 1.07)		1.04† (1.00 – 1.08)	
Married				0.12^{\dagger} (0.02 - 0.62)		
≥High School		0.16† (0.03 – 0.86)				
Annual Household Income ≥ \$70K					3.78† (1.22 – 11.68)	
Involuntarily out of Work	0.09^{\dagger} (0.01 - 0.95)					
Clinical Characteristics						
Disease Duration, Years						
No Flare past 3 months						3.39† (1.10 – 10.49)
Current Remission						
Activity past 3 months, 10-pt VAS						
Pain past 3 months, 10-pt VAS	1.49† (1.09 – 2.02)	1.51^{+} (1.09 - 2.02)				
Fatigue past 3 months, 10-pt VAS		1.39† (1.06 – 1.83)	1.24† (1.04 – 1.47)	1.49‡ (1.20 – 1.83)		1.33‡ (1.10 – 1.59)
Symptom Severity Since Diagnosis, 10-pt VAS						
Social Network Characteristics						
MOS Social Support Scale, higher scores = more support available		0.82; (0.72 - 0.94)	1.14^{\dagger} (1.02 – 1.28)	0.87^{+}_{-} (0.77 – 0.98)		
Lubben Social Network Scale, higher scores = larger/tighter networks						

IN: Independent, DE: Dependent, US: Not Independent/Under-Supported

Pr > Chi Square: †p<0.05; ‡p<0.01