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ILLNESS NARRATIVES OF WOMEN WITH SYSTEMIC LUPUS
ERYTHEMATOSUS AND FAMILY COMMUNICATION: A MIXED METHODS
STUDY

by

Katherine M. Castle

A DISSERTATION

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ILLNESS NARRATIVES OF WOMEN WITH SYSTEMIC LUPUS
ERYTHEMATOSUS AND FAMILY COMMUNICATION: A MIXED METHODS
STUDY

Katherine M. Castle, Ph.D.

University of Nebraska, 2015

Advisor: Jody Koenig Kellas.

Systemic lupus erythematosus (SLE) is a prominent, yet under-studied autoimmune condition that is both life limiting and potentially life threatening and affects more than one million Americans, primarily women. Despite this, the disease continues to go undiagnosed and unmanaged, leading to more severe outcomes of the disease process. Though there is growing recognition of the importance of social behaviors in improving health outcomes, particularly family communication and sense-making, there is a paucity of research aimed at understanding the experience of SLE and how women make sense of the disease in family contexts. This exploratory sequential mixed methods project is framed in the over-arching theory of communicated narrative sense-making (CNSM, Koenig Kellas & Kranstuber Horstman, 2015). Grounded in the CNSM framework of retrospective storytelling and guided by Frank's (2013) typology of illness narrative types and McAdams' (1993) conceptualization of narrative tone, Study 1 employs qualitative methods to explore the illness narrative plotlines that animate the communication of women with SLE. It further explores the family communication behaviors that women describe as characterizing their SLE experience. Study 1 found six SLE narrative plotlines (i.e. ambivalent life-as-normal, ambivalent chaos, contaminated life-as-normal, ambivalent quest, contaminated restitution, and redemptive quest), four

family communication behaviors (i.e. openness, avoidance, confirmation, and disconfirmation), and three SLE family myths (i.e. harmonious, abandoned, battle). Study 2 builds from these findings to integrate the qualitative findings into the quantitative strand of this research project and to quantitatively examine relationships between the SLE narrative plotlines and SLE family myths and measures of health and well-being as well. Study 2 found that narrative sense-making, both the individual SLE narrative plotlines and the gestalt SLE family myths, had implications for physical health, mental health, and family satisfaction in SLE. The implications for this study as a foundation for the development of interventions for family members, patients, and physicians working and living within the context of SLE are discussed.

DEDICATION

This dissertation is dedicated to my husband and three children, without whom none of this would have been possible. My husband, Jason Castle, deserves special recognition. He has always believed in me and in us, and has been my rock throughout our married life, of which this particular endeavor is just one part. Jason has the most incredible ability to balance and prioritize all the important elements of life—and his incredible dedication to our family and his commitment to pursuing our dreams have been what has made this journey possible. Not only has he provided me with strength, unconditional love, and encouragement along the way, he has been instrumental in helping our family maintain a healthy balance between work and play. It was his willingness to take on so many of the day-to-day responsibilities and stress of family life that enabled me to strike a comfortable balance between scholar, wife, and mother—a balance that was necessary for me to successfully walk this path these last four years. He is the love of my life, an incredible husband and partner, and an even more amazing father to our three children.

Our three children, Julia Castle, Tyler Castle, and Ava Castle, have also been instrumental in this accomplishment. Their patience, support, love, and pride in this pursuit has served as fuel for this journey. Each one of them has shown support in so many different ways, though a few things stand out as worth mentioning here.

Julia has always taken an interest in the topics of my studies—asking questions, offering thoughts and insights, and setting her books up next to me so we could study together. I have always valued our discussions about research and the impact it can have on improving our world. Most recently, her reflection on and appreciation of the fact that, after being diagnosed with SLE myself, I centered my dissertation research on the

experience of SLE in the hopes of improving the health and well-being of those struggling with SLE, served to confirm for me that our children see the real-world impact of educational pursuit. Her insights always amaze me and I look forward to seeing where her intellectual curiosity takes her in life and to many more thought-provoking and heartfelt discussions over the years. I am so blessed to be her mother.

Tyler has been tenacious in his support of this goal—he has always been able to sense when the balance between family and scholarly pursuit felt overwhelming to me, stepping up with a well-timed “You can’t give up, Mom, I’m so proud of you!” His passion for the importance of this pursuit and his unwavering confidence in me have been more important to me than I can express. He is, without a doubt, an incredible son. I look forward both to supporting him wherever his commitment, tenacity, and passion take him and celebrating his many inevitable accomplishments.

Ava’s big heart and unconditional love have also been instrumental to this journey. Her patience with this process is unparalleled. After a full day of work and a full evening of reading and writing, Ava was always right there to sit and cuddle with me, make me laugh, tell me that she loves me, and make me feel so special even as I sat there exhausted from the demands of the day. She has always been able to help me re-focus my attention onto our family even during my most stressful times over these last four years. She is a true blessing, and I look forward to both many more cuddles and laughter and to seeing how she ends up putting her unique personality and talents together to make her dreams come true.

I am so proud of each of each member of our family and the way we all worked together to earn this Ph.D. I am so grateful for each of them and their unconditional love

and support. I hope and pray that the path our family has followed will inspire our children to find happiness both in the pursuit of their dreams and in the love, comfort, and support of their families.

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I would also like to thank the women who shared their SLE experiences with me in interviews or surveys. Their stories have shaped my own sense-making about SLE in powerful ways. I am so appreciative of their trust and candor, and look forward to building from what I've learned to improve how we live with and relate in SLE.

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CHAPTER 1

INTRODUCTION

Systemic lupus erythematosus, known as either systemic lupus or SLE for short, is a chronic, inflammatory multi-system autoimmune disease that is life-threatening, affecting more than one million Americans combined, making it “more common than leukemia, multiple sclerosis, cystic fibrosis, and muscular dystrophy *combined*” (Wallace, 2008, p.3). Women comprise 90% of SLE patients in the United States (Aberer, 2010; Wallace, 2008). The disease is characterized by a failure of the immune system to differentiate between antigens and the body’s own cells and tissues, resulting in the body essentially attacking itself. SLE is often misunderstood and misdiagnosed because it presents in such varied ways (Aberer, 2010; Wallace, 2008), complicating the means by which lupus patients and their families understand and orient to the disease.

Despite the fact that families and health are inextricably intertwined through communication and the majority of the sense-making about illness occurs in family communication processes (Pecchioni & Keeley, 2011), there exists a clear communication gap between lupus patients and their families. A 2011 Roper survey of 950 individuals affected by lupus indicated that most lupus patients downplay their symptoms to their family members; lupus patients often feel their illness experience is doubted by their loved ones; and the disease strains every relationship they have (Roper Public Affairs, 2011). Good family communication and the social support and coping resources it provides (Pecchioni, Overton, & Thompson, 2015) is clearly linked to positive health outcomes in chronically ill individuals (Rosland, Heisler, & Pettit, 2012).

Thus family communication is of central concern to the health and well-being of women struggling with SLE.

Family communication and illness shape and are shaped by one another. Families serve to both socialize us to adopt specific attitudes and behaviors associated with health and illness and provide us with social support and coping resources vital to positive health outcomes (Pecchioni et al., 2015; Rosland et al., 2012), two fundamentally important processes in shaping attitudes and behavior. Family communication influences patients' willingness and ability to comply with medical directives (DiMatteo, 2003) and even shapes what information patients share with their physician, ultimately influencing medical decision-making (Lindenmeyer, Griffiths, & Hodson, 2011).

Family communication is also central to the ways in which patients and families make sense of illness with one another (Koenig Kellas & Kranstuber Horstman, 2015). The way individuals and families make sense of illness shapes patient orientations toward their illness and their medical providers. Further, it shapes the patient and family's ability to cope with the demands of the illness (Sharf & Vanderford, 2003). Chronic illness in general, and SLE in particular, is characterized by a loss of control including unpredictable disease activity and increased physical symptoms such as fatigue and a loss of energy which lead to diminished social relationships (Aberer, 2010; Sharf & Vanderford, 2003; Mendelson, 2006; 2009). Frank (1995, 2013) asserts in addition to all of this, the illness experience results in a loss of *voice*. Thus, chronically ill individuals cope with this loss by making sense of it through communication.

One primary way to make sense of an experience that is characterized by uncertainty, a loss of self, and a loss of control (Charmaz, 1983, 1995, 2000) is through

narrating the difficulty. In constructing personal illness narratives, chronically ill individuals are able to recover their voice and regain some control as they author their illness experience, creating an order to these events and providing a framework for understanding the future in illness. Thus, narrative sense-making provides the foundation for individuals and families to assert some level of control as it provides a mechanism for coping and identity (re)construction throughout the illness experience (Sharf & Vanderford, 2003). Given that narrative sense-making is inherently communicative, communicated narrative sense-making (CNSM, Koenig Kellas & Kranstuber Horstman, 2015) provides the theoretical foundation for this project.

Studying SLE through a narrative lens is important because one of the difficulties in studying the experience of chronic illness is that it has often been reduced to one unifying view of illness (Leventhal, Idler, & Leventhal, 1999) rather than recognized and championed for the idiosyncratic experience of individual patients as they manage the disease in their own lives (Frank, 2013). Historically, this general unifying view of illness has inhibited the more nuanced understanding of the illness experience that is necessary to be true to those experiencing it. This is particularly true for women with SLE as patients are often described as snowflakes with no two SLE experiences presenting exactly alike, and in many cases, not even in similar ways (Mendleson, 2006). Thus, a narrative lens allows for an examination of the socially constructed realities of women's SLE experiences.

Further, SLE is potentially life threatening and is often a life limiting disease when left undiagnosed and untreated (Wallace, 2008). It is a disease in which communication with key stakeholders is often inhibited and every relationship becomes

strained (Roper Public Affairs, 2011). It is therefore essential that the experience of systemic lupus be studied in a way that is truly representative of this under-studied and often misunderstood population. Research focused on this population must strive to both honor the diversity of experience as well as provide clear insight into strategies that will yield better health outcomes. Though personal illness narratives are idiosyncratic, they are often guided by and drawn from definitive narrative types that are accessible to individuals experiencing illness (Frank, 1995, 2013). Thus, this dissertation is designed to identify the illness narrative types that guide sense-making in women with SLE as a means to identify commonalities across personal narrative sense-making in SLE and correlate these narrative types with family communication behaviors and measures of physical, mental, and relational health and well-being. Mixed methods research guided by narrative theorizing provides the ideal framework for achieving these research objectives.

Mixed Methods Research

Mixed methods is defined as research that collects and integrates qualitative and quantitative data to harness the advantages of both by enabling a fuller understanding of a complex research problem (Creswell, 2015). A key reason for using mixed methods research is to simultaneously enhance the representation of a specific population in honoring its idiosyncrasy and provide a legitimization of the ways the findings in this population can generalize to the larger population (Creswell, Klassen, Plano Clark, & Smith, 2011). One criticism of mixed methods research stems from a long-standing tradition of paradigmatic debates (Creswell, 2015; Lincoln, Lynham, & Denzin, 2011) that render the use of multiple or blended paradigms nearly incomprehensible to some.

Because of this, I begin this mixed methods project with an in depth discussion of the guiding paradigmatic orientations.

Specifically, I see all worldviews as inherently incomplete and necessary to conduct solid programmatic research. In considering this idea as it relates to individual researchers, I follow Greene (2007) as she complicates the idea of neat, categorical paradigms. She conceptualizes paradigms as informing mental models that guide social inquiry. These models are drawn from multiple paradigmatic orientations and create space for researchers to acknowledge both the value and inherent limitations of paradigms as sensitizing orientations and to creatively draw from multiple paradigms to guide their research projects. Others are recognizing the trend toward multiple paradigmatic orientations as is evidenced by Lincoln and colleagues' (2011) claim that some paradigms formerly thought of as incommensurable are beginning to productively interbreed. I depart from their line of thinking when they assert that post-positivist and constructivist paradigms are incommensurable. In fact, I subscribe to both the social constructivist (i.e. reality is subjective and co-constructed in communication throughout the research process) and the post-positivist (i.e. reality is objective and approximated in the research process) paradigms and each of these is at work in this proposed mixed methods project.

This project embraces an ontological philosophy that reality is socially constructed through communication, and following Berger and Luckman (1966), positions identifiable social structures as reifications of social interaction. In other words, reality is socially constructed in patterned ways and these reifications of social structures are treated as objective by actors in the social world (Miller, 2000). In this way, reality is

both socially constructed in interaction and is simultaneously discoverable in that the dominant understandings of a culture are patterned. Narratives are one such socially constructed phenomena that are accomplished in relation to others (i.e. social constructivist paradigm, Harter, 2013) that occur in patterned ways (i.e. post-positivist paradigm, Koenig Kellas & Kranstuber Horstman, 2015).

Defining Narrative in this Mixed Methods Project

Narrative research has many forms (Creswell, 2013) and continues to emerge as it provides a framework for exploring diverse questions and ideas (Chase, 2005). Given the interdisciplinary (Marshall & Rossman, 2011) and rich, diffuse tradition of narrative research (Chase, 2005), it is not surprising that narrative researchers use inconsistent terminology and emphases when conducting this research. For example, some use the term narrative to refer to a form of research inquiry that explores the stories of one individual (i.e. Creswell, 2013) while others use the term narrative interchangeably with the word “story” to refer to the specific stories that people tell in relating experiences (i.e. Labov & Waltezky, 1967). Some focus their interest in narrative on storytelling, or the *process* of telling these stories as they constitute experience (Koenig Kellas, 2005; Koenig Kellas & Trees, 2013), while others use the term narrative to refer to an organizing framework that serves as a resource for making sense of experience (i.e. Elliott, 2005; Frank, 2013; Harrington, 2008). In the midst of this myriad of approaches to narrative research, Bruner (2004) asserts “I believe that the ways of telling and the ways of conceptualizing that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for not only guiding the life narrative up to the present but directing it into the future” (p. 708). Based

on this important idea, I define narrative as a socially constructed sense-making framework that affects and reflects the communication of knowledge, particularly the sharing of stories. I am particularly interested in narratives in the context of difficulty. Narratives' sense-making framework is derived from cultural, institutional, family, and relational stories (Japp, Harter, & Beck, 2005) and facilitates coping in that it enables both relating and meaning making (Bochner, Ellis, & Tillman-Healy, 2000) as individuals make sense of experiences together.

Bochner, Ellis, & Tillmann-Healy (2000) assert that narratives serve as both a way of knowing and a way of participating in the social world. Thus, I see narratives as social phenomena constituted through relational talk that act as frameworks that facilitate two fundamental social processes—*relating* (Frank, 2010) and *meaning making* (Koenig Kellas & Kranstuber Horstman, 2015). As social phenomena, narratives are constituted through talk in context (Harter, 2013) and thus specific types of narratives can be identified, observed, and studied as shaping and being shaped by talk in specific contexts. In health contexts, narratives are relational accomplishments that constitute knowledge of self and other (Harter, 2013) and serve as frameworks for making sense of difficulty (Koenig Kellas & Kranstuber Horstman, 2015). Narrating illness is inherently a communicative process and, as such, can be productively conceptualized in the context of managing a chronic illness like SLE using Koenig Kellas & Kranstuber Horstman's (2015) theory of communicated narrative sense-making. CNSM provides a theoretical framework that enables the researcher to move between paradigmatic orientations (Braithwaite, 2014) in a mixed methods project. Further, it supports the growing trend that Denzin and Lincoln (2011) observe toward researchers blending paradigmatic

orientations in research projects. Though combining social constructivism and post positivism in one research project is not a common approach to the study of social processes, Koenig Kellas & Kranstuber Horstman (2015) have asserted communicated narrative sense-making (CNSM) as a model of narrative theorizing that conceptualizes the functions of narrative and provides a framework for conducting post-positivist narrative research. I argue that this model bridges these two unlikely paradigmatic orientations in a productive and potentially ground-breaking way that is ideally suited for this project as described fully in the section below.

In short, this research project constitutes an exploratory sequential mixed methods research design, or a design that begins with a qualitative strand, moves to an integration phase in which the researcher integrates findings from the qualitative strand into the design of the quantitative strand, and ends with a quantitative strand. This approach enables me to better represent (Onwuegbuzie & Teddlie, 2003) the experience of women with SLE using qualitative methods to first explore these experiences in depth, and then build from those experiences to generalize, or legitimate (Onwuegbuzie & Teddlie, 2003) these findings as representative of the larger population of women with SLE . Study 1 is the qualitative strand of this project and was designed to identify women's SLE illness narratives as well as to understand the family communication behaviors that characterize the experience of SLE. In moving into Study 2, I propose that for the integration stage of this project, I transform the family communication behavior themes and SLE narrative plot lines that emerge in Study 1 into a population specific variable that can be correlated with individual, physical, and mental health and well-being. In this way, I can position this under-studied population for research that can provide the means to develop needed

interventions specific to this population aimed at improving family communication and ultimately, the experience of SLE. In order to clearly demonstrate how the proposed quantitative study for this dissertation project builds from the qualitative pilot study, the rest of this chapter will focus on presenting the theoretical model guiding both studies. Chapter 2, then, provides an in depth explanation of the rationale and methods for the qualitative Study 1 that provides the basis for the proposed quantitative Study 2 for this dissertation project.

Communicated Narrative Sense-Making

Communicated narrative sense-making (CNSM) is the theory that guides this mixed methods project. It facilitates the study of how narrative works in families in patterned ways and then provides the framework for correlating the patterned nature of narratives with physical, mental, and relational health and well-being (Koenig Kellas & Kranstuber Horstman, 2015). The communicative nature of narratives is at the heart of CNSM (Koenig Kellas, 2005), suggesting that they result from collaboratively constructed storytelling interactions (Koenig Kellas & Trees, 2006) and/or the interactions between story-tellers and story-listeners (sunwolf, Frey, & Keranan, 2005). However, as demonstrated and guided by the seminal work of Frank (1995; 2013) and McAdams (1993), narratives are primarily conceptualized and studied as psychological constructs (Koenig Kellas, Trees, Schrodtt, LeClair-Underberg, & Willer, 2010). As Koenig Kellas (2005) argues, it is vital that we begin to understand the communicated nature of narratives. One way we can do this is to understand and study the ways in which communication affects and reflects our personal narratives (Eisenberg, 2001).

Situated as a subset of communicated sense-making (CSM), CNSM highlights the centrality of narrative in sense-making processes associated with the fundamental narrative functions of coping, socialization, and identity (re)construction. In essence, this model both positions narrative as the medium through which these sense-making processes occur in families and theoretically links these processes to health and well-being (Koenig Kellas & Kranstuber Horstman, 2015). In order to highlight the communicated nature of narrative sense-making, Koenig Kellas & Kranstuber Horstman (2015) organize research using CNSM into a focus on the process and/or content of retrospective storytelling, interactional storytelling, and translational storytelling. In research focused on retrospective storytelling, researchers focus on the stories that people tell as well as the stories they recall telling or hearing in the family that had an impact on their development, values, or well-being. Research focused on interactional storytelling is focused on the process of (joint) storytelling in the family. Finally, research on translational storytelling focuses on how narrative theory, research, and methods can inform interventionist efforts that will help families cope with or manage difficult experiences (Koenig Kellas & Kranstuber Horstman, 2015). This particular research project falls within the purview of retrospective storytelling as it focuses on identifying the illness narrative types at work in the sense-making processes of women with SLE through their articulation of their illness story as well as through their recollections of family communication and stories important to their illness experience. Retrospective storytelling about significant family events – such as illness – allows narrators to construct identity and cope in light of difficulty. These stories illustrate the meaning women have assigned to SLE both as it pertains to their own and their family's identity.

Further, this project is designed to contribute to the translational potential of narrative in that the data collected from this project will be used to inform interventions for women and families managing SLE in order to teach them how to communicate in ways that may yield a more productive SLE narrative.

Unlike most approaches to narrative (Bochner et al., 2000; Sharf & Vanderford, 2003), CNSM takes a post-positivist approach to explore how socially constructed narratives correlate with health and well-being. Thus, CNSM is not only an ideal fit with the paradigmatic foundations of this research project (i.e., social constructivist and post-positivist), it clearly encompasses both Study 1 and Study 2 of this research project in that it creates space for the emergent nature of narratives and facilitates examining correlations between narratives and communication behaviors as well as important health outcomes.

Chapter Summary

Health transitions like the onset and management of SLE shape and are shaped by communication in families (Miller-Day, 2011) and narratives are a primary way in which individuals make sense of illness (Frank, 2013; Sharf & Vanderford, 2003). Thus, examining women's SLE narratives offers a window into both individual and family culture (Koenig Kellas & Trees, 2013) which is needed given the growing prevalence of SLE, but the limited understanding of how people cope with and make sense of this disease. The purpose of this mixed methods research project is to understand how lupus narratives emerge in family communication and what the health and relational implications of specific SLE narratives are for women with SLE. Though narratives have been explored in sociological (e.g., Frank, 2013), psychological (e.g., McAdams, 1993),

therapeutic (e.g., White, 2007), medical (e.g., Charon, 2006) and increasingly, communicative contexts (e.g., Koenig Kellas, 2005; Koenig Kellas, 2010; Koenig Kellas & Kranstuber Horstman, 2015), very little research has focused on how family communication affects and reflect the illness narratives SLE women tell. Further, though the articulation of illness narratives has been shown to facilitate agency and sense-making in illness (Sharf & Vanderford, 2003), no research has examined how narratives in this context relate to health and relational well-being.

In order to fill these gaps and paint a richer picture of the individual and family communication experience and sense-making process of SLE women, this project is a mixed methods project consisting of two studies. The intent of Study 1 is to qualitatively identify SLE narratives and understand family communication behaviors in the context of SLE. The intent of Study 2 is to quantitatively evaluate links between these SLE narratives, family communication, individual and relational health for women with SLE. The implications of narratives for women making sense of the experience of systemic lupus should inform the development of interventions aimed at helping families and patients communicate in ways that yield productive and healthy narratives of systemic lupus. This dissertation consists of two studies that are integrated to inform our understanding of narrative sense-making in SLE. Thus, Chapter 1 is the introduction to the mixed methods project. Chapter 2 is the rationale for Study 1, while Chapter 3 presents the methods for Study 1, Chapter 4 details the qualitative findings and Chapter 5 presents the discussion of Study 1. Chapter 6, then, builds from these findings to develop the rationale for Study 2 and Chapter 7 presents the methods for Study 2. Chapter 8 then

presents the findings of Study 2 and Chapter 9 presents the discussion of Study 2. Finally, Chapter 10 presents an overall discussion of the mixed methods project.

CHAPTER 2

STUDY 1 RATIONALE

Family communication shapes and is shaped by illness. Family cohesiveness, perceived social support within the family, and open communication about illness and its implications as perceived by an ill person have all been shown to positively impact self-management behavior, increase the likelihood that the disease will be controlled, and have the potential to reduce mortality rates (Rosland et al., 2012). Further, illness changes social relationships (Beach, 2002). Family communication, then, is critical to navigating illness, and is central to sense-making throughout the illness experience (Pecchioni & Keeley, 2011). Despite this growing evidence supporting the importance of family communication in illness, there is surprisingly little research focused on the interdependence of family and health communication processes (Miller-Day, 2011), highlighting an important opportunity for family communication researchers to conduct research that will contribute to the ability of patients, families, and healthcare providers to successfully manage chronic illness in a healthcare context shifting its focus from acute to chronic illness (Allen, Wainwright, & Hutchison, 2011).

SLE has been studied from a narrative perspective (i.e. Mendelson, 2006, 2009), though this work was ethnographic with a focus on gaining an in-depth description of what daily life is like for women living with SLE. For example, Mendleson's (2006) analysis of women's stories of lupus revealed that the central phenomenon is that they live socially and medically complex lives characterized by uncertainty, shifts in identity, and financial burden. Further, in a case study analysis of the same data set, Mendelson (2009) found that the narratives of women with SLE were predominantly focused on

seeking a diagnosis. Mendelson (2009) ultimately concluded that the absence of a diagnosis held women's identity construction in abeyance, inhibiting the development of a coherent narrative and impeding the sense-making process. Given that identity (re)construction is fundamentally a sense-making process that occurs in communication (Koenig Kellas & Kranstuber Horstman, 2015) throughout the illness experience, both pre and post-diagnosis, (Charmaz, 2000), I argue that narrative identity (re)construction and narrative coping are continuous, emergent processes that occur in light of and despite diagnosis. Thus, these ever-emergent processes of narrative identity (re)construction and coping affect and reflect family communication and health and well-being in the context of illness. This study, then, is positioned to build from and extend Mendelson's (2006, 2009) findings in exploring the communicative nature and implications of narrative sense-making in families in the context of SLE.

Further, strained family relationships so often associated with an SLE diagnosis (Roper Survey, 2011) can impede the process of sense-making in SLE given that families are central sites for sense-making (Pecchioni & Keeley, 2011). The way individuals and families make sense of illness shapes patient orientations toward their illness (Villagran & Sparks, 2010), their ability to cope with the illness (Frank, 2013), and their willingness and ability to comply with medical directives (DiMatteo, 2003). Sense-making processes also shape patient and family orientations toward their medical providers (Charon, 2006) and what information they share with them, ultimately impacting medical decision-making processes (Lindenmeyer et al, 2011). Thus, another focus of this study is understanding narrative sense-making in SLE.

Based on the importance of individual and family-level sensemaking in the context of SLE, the current study is grounded in narrative theorizing. Two primary functions of narratives relevant to the current study include identity construction and sense-making, or coping. SLE involves a need to cope with difficulty (Frank, 2013) and (re)construct identity in the face of illness (Charmaz, 2000). Sharf & Vanderford (2003) explain that “narrative form puts the ‘I’ back into a person’s understanding of his or her life” (p. 21), thus serving as a vehicle for agency in the process of coping with and (re)constructing identity central to the experience of illness (Charmaz, 2000). Therefore, narratives offer an appropriate means for understanding the experiences and communication of SLE women. Located within the broad conceptual framework of CNSM, this study theoretically positions retrospective storytelling as an important means by which women narrate their SLE illness experience, position their own identity in relation to the illness, make sense of the ways in which the family communication affects and reflects the narrative coping process. In addition to acting as a heuristic call for research on the links between communicated narratives and psychosocial well-being, CNSM is also a framework for organizing the impact of extant research and theorizing on our understanding of these links. In line with this approach and in order to understand the power of identity construction and coping in the process of retrospectively narrating SLE, I further draw theoretically from Frank’s approach to illness narratives and McAdams’ (1993) theory of narrative identity to examine SLE narratives.

Narrative Coping

One fundamental function of narratives in family contexts is coping with difficulty (Koenig Kellas & Kranstuber Horstman, 2015), and coping is one of the

fundamental functions of family communication (Pecchioni et al., 2015). Narrative coping in the family has been found to benefit families in a wide array of difficult contexts (Koenig Kellas & Kranstuber Horstman, 2015). In a recent review of the impact of family communication behaviors on illness management, for example, Rosland and colleagues (2012) found that the most effective way for families to enhance coping mechanisms is by using active, problem focused strategies rather than avoiding discussions of illness management. Given that narrative sense-making facilitates a reclamation of control and agency in the midst the uncertainty and ambiguity of illness (Sharf & Vanderford, 2003), family support focused on problem solving must involve enabling telling and listening to stories of illness during SLE.

Narratives have increasingly been studied explicitly in the context of illness (Frank 1995, 2013; Kleinman, 1988; Sharf & Vanderford, 2003) and this increased attention has led to the identification of specific narrative *types* that characterize the illness experience and reflect the various means by which people cope. Frank refers to these as culturally available plots that underlie the experience of illness (Frank, 1995; 2013). These personal illness narratives serve to not only reflect the experience of illness, but to give it meaning and significance (Kleinman, 1988). Though people tell their own unique stories and co-construct their own personal narratives, Frank (2013) theorizes that personal narratives of illness are derived from an adaptation and combination of socially available narratives, positioning narrative type as “the most general storyline that can be recognized underlying the plot and tensions of particular stories” (Frank, 2013, p. 75). He has delineated six distinct types of illness narratives that aid in coping with illness. These include the restitution narrative, chaos narrative, quest narrative, life-as-normal narrative,

broken narrative, and borrowed narrative. In providing a mechanism by which people can tell and listen to illness stories, these narrative types facilitate relating as well as sense-making as people cope with the ongoing difficulty of managing chronic illness.

Of course, the experience of illness is fluid and individuals move between these illness narrative types as they experience their illnesses over time. Thus, Frank's (2013) distinct types of illness narratives can lend some insight into each participant's *current* conceptualization of her illness. Given that narratives both shape and are shaped by human conduct (Frank, 2010) as constituted in communication (Berger & Luckman, 1966), in identifying which illness narrative type is reflected in women's communication about SLE using this typology as a sensitizing framework, I can both better understand sense-making in SLE and position myself and others to identify the implications of each narrative type for physical, mental, and relational health and well-being.

Frank's Typology of Illness Narratives

In his seminal work on illness narrative types, Frank (1995, 2013) delineated six illness narrative types. These have come to serve as a foundation for understanding the various cultural narratives available to and adopted by people coping with illness, though research has yet to validate the existence of this typology in an illness context like SLE, nor has it yet explored how these narrative types emerge in communication about and through the chronic illness experience. Frank's illness narratives serve as master narratives, of sorts, from which individuals draw and place their own personal stories of illness. The *restitution* narrative is the dominant biomedical narrative of illness, with the triumph of medicine as the main plot, and "they are self-stories only by default" (Frank, 2013, p. 115). The remedy for the ailment (either a drug, a therapy, a physician) is the

star of the stories. In this narrative, the person gets sick, seeks treatment from a medical provider who serves as the hero in the story by providing treatment and helping the patient return to good health. It is a story of recovery and triumph through medical intervention.

The *chaos* narrative is characterized by an absence of control, is not cohesive in that it has no discernable narrative order, and it is told as it is experienced, by the ill person. Often, those working within this narrative seem to relate their experiences as one difficulty after another (i.e. “this happened, and then this happened, and then this, and then this...”), with no sense of reflection or meaning-making apparent. This narrative is a more difficult narrative to tell and to hear because it is difficult to articulate given that it is “told on the edges of speech” (Frank, 2013, p. 101). These are also difficult to witness because listeners do not often wish to acknowledge the reality of illness as it is presented in this narrative. Ultimately the *voice* of the teller is lost in the chaos of this narrative.

The *quest* narrative is comprised of stories that meet illness head on, accept suffering, and seek to use it to gain something from the experience of illness. In this narrative, suffering is the mechanism through which the teller becomes the hero. The goal is not to be restored to how the person was prior to illness as is the case in the restitution narrative, but is to make sense of the illness and the self after the illness as somehow marked in a positive way from the journey. The ill person, though having suffered, became better through suffering. Thus, in this narrative, the teller reclaims her/his voice in the story as the teller embarks on a journey of illness through which s/he searches for an alternative way of being ill and of suffering.

Life-as-normal narratives are narratives in which life continues as normal so that illness related changes to relationships can be minimized. The illness is either excluded or minimized in these stories, and normality is viewed as a good story for the moment. The life-as-normal narrative is what Frank (2013) refers to as a narrative in abeyance, or one waiting to be told.

The *borrowed* stories narrative is one that is told when the teller lacks the narrative resources to make sense of the illness experience. These are co-constructed stories from which the sufferer borrows and adapts cultural stories to fit her own individual experiences with illness. This narrative is often found with children attempting to make sense of their suffering in illness through images and scenes from media and/or from stories to which they've been exposed that help provide a frame for an otherwise incomprehensible experience. These borrowed stories serve as resources to help communicators find creative space for interaction as they seek to make sense of an illness experience for which they do not have access to other applicable narrative resources (Frank, 2013).

Finally, Frank (2013) identifies *broken* narratives as narratives of those that do not have the capacity to narrate due to the effects of illness on their bodies. Broken narratives characterize the experience of advanced Alzheimer's patients as well as those who are no longer able to speak who can no longer narrate their story in a coherent manner. They often rely on their caregivers to provide coherence to their experience and thus these stories are necessarily collaborative and co-constructed, and are inherently moral acts on the part of the co-narrator. These narratives are comprised of shared stories

and help the ill person narratively connect the present to the past and future (Frank, 2013).

Frank's (1995, 2013) typology of illness narratives represents a framework for understanding common plotlines that animate personal illness narratives differently over the course of an illness experience. In the current study, I expect that restitution, chaos, quest, and life-as-normal narrative types will be the most prevalent in women's experience of SLE.

Though these illness narrative types speak to the plot of the story, they do not speak to the way the storyteller evaluates the plot of their illness narrative. The evaluation of a narrative is central to narrative sense-making (Labov & Waletzky, 1967), thus, the way a story is told is as important as the story itself (Frank, 2010; McAdams, 1993). It is therefore important to consider not just the plotline, but also the way the storyteller presents the narrative. One way to examine this is through an analysis of the tone or affect of the narrative as it is presented by the narrator.

Narrative Tone

Along with coping, CNSM (Koenig Kellas & Kranstuber Horstman, 2015) positions identity construction as a primary function in narrating difficulty. McAdams (1993) presents narrative identity as the communicative construction of a personal myth that serves as a "patterned integration of our remembered past, perceived present, and anticipated future" (p. 12). He posits that ideally, our lives are a coherent story that accounts for all of our experiences and orders them in a sequence that promotes this cohesiveness. Illness, however, represents a disruption (Charmaz, 1983, 1995, 2000) to this coherent story and often contributes to the emergence of an incoherent account of the

self. Thus, narrative sense-making not only facilitates coping, but serves to (re)construct a sense of self in the face of illness. In turn, identity (re)construction throughout the experience of illness is central to coping with it (Charmaz, 2000).

Narrative tone is central to narrative identity (re)construction, and thus, coping with illness, and refers to the overall emotion or attitude of the narrative that someone tells, whether it is positive and optimistic or negative and pessimistic. It is expressed in both the content of the story and the manner in which the story is told (McAdams, 1993; 1996). McAdams (1993) asserts that the tone of an individual's narrative reflects the presence or absence of dispositional optimism, which is a general expectation for good rather than bad outcomes to occur in any given situation. Dispositional optimism has been linked to positive effects on coping with illness (McAdams, 1993). A redemptive narrative is characterized by stories told in a way in which bad events that occur are expected to give way to a good outcome. This is a positive tone that displays the presence of dispositional optimism.

A contaminated narrative is characterized by stories that are told in which bad events are expected to remain bad or get worse (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001). This is a negative tone that reveals an absence of dispositional optimism. Some narratives do not convey a strong positive or negative tone and can therefore be considered ambivalent (Koenig Kellas et al., 2014). Thus, the tone imbued in the way women talk about their illness experience will reveal important information about the ways in which they cope with the illness and how they have incorporated it into their overall identity as they (re)construct throughout illness. For example, as a narrative type, Frank's (2013) restitution narrative that tells an overall story of restoration to the

pre-illness state, could be redemptive (e.g., characterized by hope for recovery), contaminated (e.g., characterized by the expectation of inevitable failure), or ambivalent (e.g., told without a great deal of affect). Narrative tone, then, provides an important nuance to the analysis of illness narrative types in that it lends insight into the narrator's affect regarding the illness experience, thus providing a way to delineate important distinctions within illness narrative types that may prove important in subsequent analyses related to health and well-being.

Thus, in order to identify the narrative that is guiding sense-making – and therefore the individual experiences of coping and identity construction in SLE – it is important not only to examine the content of the narrative to identify the type (Frank, 1995; 2013), but also to examine the tone of the narrative (McAdams, 1993), or how the way the narrative is told reflects the participant's perception of the illness experience (i.e., whether it is redemptive or contaminated). Thus, I argue that an analysis that includes attention to both the distinct illness narrative type (i.e. Frank's 2013 typology) and narrative tone (i.e. McAdams 1993 narrative tone) comprises distinct and identifiable *illness narrative plotlines* that guide the sense-making process of women with SLE. Thus, the first research question, guided by an analysis of content and tone, is:

RQ1: What, if any, illness narrative plot lines, as constituted by illness narrative types and narrative tone, characterize the experience of women with SLE?

In exploring the illness narrative plot lines that characterize women's experience with SLE, Study 1 positions me to identify narrative commonalities across the idiosyncratic experiences of women with SLE, honoring the unique experience and enhancing the representation of this unique population (Onwuegbuzie & Teddlie, 2003).

Family Communication and Illness

The impact of SLE on family relationships (Roper Survey, 2011) has significant implications considering the growing evidence that social behaviors shape illness outcomes (Shapiro, 2002) and that family communication and social support are clearly linked to improved health outcomes in chronic illness (Rosland et al., 2012). Families have been found to be primary sites for sense-making in illness (Pecchioni & Keeley, 2011) as it is through family communication that individuals are socialized into certain attitudes, behaviors, and beliefs (Koenig Kellas & Kranstuber Horstman, 2015). Further, family communication provides social support and coping resources when an individual is faced with difficulty (Pecchioni et al., 2015; Rosland et al., 2012). One fundamental way in which families provide these resources is through family storytelling (Koenig Kellas, 2010). Humans are inherently storytellers (Fisher, 1987) and narratives are knowledge (Bruner, 2004). Family storytelling, then, is the communication of that knowledge and thus serves to shape and is shaped by the underlying plot, or narrative framework (Frank, 2013), that guides an individual's sense-making process. For example, Bruner (2004) asserts that formal structures for experience are laid down early in the discourse of family life and these formal structures persist despite the changing circumstances that characterize the illness experience. These formal structures, or narratives, are therefore constructed in and through family communication, have implications for family communication, are primary resources for sense-making (Koenig Kellas & Kranstuber Horstman, 2015), and are well-suited to studying the transitions (Holmberg, Orbuch, & Veroff, 2004) associated with living with and negotiating an illness like SLE in a family context.

Illness, of course, shapes the way families communicate with one another. Beach (2002) found that a cancer diagnosis significantly alters social relationships. This is not surprising, given that families living with chronic illness experience increased stress (Rolland, 1994), increased uncertainty, and increased anxiety all of which leads to behavioral and communicative changes within the family (Miller-Day, 2011). Despite the importance of family support in illness, these increased stressors and demands can, unfortunately, create barriers to family communication. For example, in a study consisting of 35 in-depth, semi-structured interviews with adult children who lost a parent to lung cancer, Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown (2011) found that illness often resulted in avoidance of informational as well as emotional topics related to the illness.

Complicating this tendency toward avoidance is the increased felt anxiety and increased need family members have for information when a family member is diagnosed with a serious illness (Hay, Shuk, Zapolska, Ostroff, Lischewski, Brady, & Berwick, 2009). In their study examining family communication patterns after one member receives a diagnosis of melanoma, Hay and colleagues (2009) examined disclosure processes in illness and found that emotional closeness was one factor in determining whether or not a person disclosed illness-related information to their family members.

It is clear that emotional closeness in illness is complex, as it is both necessary to facilitate disclosure in illness and is itself inhibited in the context of illness. Family communication is clearly complicated in the chronic illness context, wrought with needs for emotional closeness and information competing with a desire to avoid disclosure in a highly uncertain, anxiety ridden context. Thus, despite the importance of good family

communication to provide support, enable coping, facilitate identity (re)construction, and promoting positive health outcomes, family communication in chronic illness is difficult, complex, and marked by competing, emergent needs. Given that narrative approaches are particularly well-suited to understanding meaning (Frank, 1995, 2013; Kleinman, 1988), a theoretical approach like CNSM centered on understanding how people communicate to narratively make sense of the complexities of illness is ideally suited to account for and understanding these competing tensions in family communication. For example, family communication behaviors that permeate the literature on family communication in illness (e.g., avoidance) likely help to explain the narrative tone and narrative type that is most prevalent in an individual's sense-making about SLE. To illustrate, if family members emphasize hope for a cure in their communication (Koenig Kellas, Castle, & Johnson, 2014), it is likely that the restitution narrative is most prevalent in their sense-making processes about SLE. Thus, this first study allows for a qualitative examination of family communication and SLE narrative plot lines in order to better understand the experience of SLE.

Family Communication and Illness Narratives

Given the centrality of families to sense-making (Pecchioni & Keeley, 2011), families are inherently central to the experience of illness. Though the protagonist in illness narratives tends to be the ill person her/himself, the family is a major part in the drama of illness. Thus, families must together do the work of making the illness a part of their construction of reality (Kleinman, 1988). In essence, the illness becomes a part of the family (Rolland, 1994) and thus, from a constitutive approach to family (Galvin & Braithwaite, 2014), its meaning and role in the family must be communicated into and

out of being. Koenig Kellas (2005) views narrative as a communicative lens on family culture and Koenig Kellas & Trees (2013) argue that family storytelling as one type of family communication affects and reflects family culture. Thus, family communication in the context of illness should shape the narrative plot line (i.e. narrative type and tone) that guides meaning making in illness.

Though Frank (1995, 2013) and McAdams (1993) each provide important theoretical lenses for understanding illness narratives and acknowledge the importance of social interaction, neither of them explain how communication shapes the narrative types and tone that they identify. Further, though Frank (2013) asserts that illness narrative types help us to make sense of illness, sense-making itself is a communicative process (Koenig Kellas & Kranstuber Horstman, 2015), and we tell stories to map out our experience (Bruner, 1991; Harter, Patterson, Gerbensky-Kerber, 2010) in order to make sense of that experience with others. Chronic illness exists over time and, as such, requires ongoing sense-making about what it means to be healthy, what it means to be ill, and ultimately, what it means for a person's sense of self to be ill with this particular illness as the illness and its impact shift over time (Charmaz, 2006).

Frank (1995, 2013) is clear that illness narrative types are all present during the illness experience, though are differently emphasized throughout the experience. In other words, though they are all present at any given time, one illness type is most prevalent and thus dominates the sense-making process in illness. Given that Frank (1995, 2013) and McAdams' (1993) theoretical conceptualization of narratives includes a recognition that narratives are constructed in interaction but neither of them address how they are constructed and the importance of family communication in narrative sense-making

(Pecchioni & Keeley, 2011), the second research question of this study is centered on family communication in SLE.

RQ2: How do women with SLE characterize their family communication?

Family Communication, Illness Narratives, and Family Identity

As reviewed above, family communication is essential to coping in illness (Pecchioni et al, 2015) and is central to sense-making (Pecchioni & Keeley, 2011). One fundamental struggle that chronically ill individuals face is the need to continuously (re)create their identities in the face of illness (Charmaz, 2000). Narrative sense-making in illness is a family experience (Kleinman, 1988) that not only functions to help people cope with illness, it helps them to (re)create their identities (Koenig Kellas & Kranstuber Horstman, 2015). Family communication and narrative sense-making also affect and reflect family identity (Koenig Kellas, 2005), and a person's perception of their family's identity shapes their personal identity (Scabini & Manzi, 2011). Given the centrality of family communication to narrative sense-making (Pecchioni & Keeley, 2011) and the fact that narrative sense-making in illness is a family affair (Kleinman, 1988), I suspect that the two work together to shape the way a person views their family in illness. However, despite the importance of an individual's perception of their family's identity, it is not clear whether and how family communication and narrative sense-making work together to shape the way a person views their family's identity in relation to their illness.

In order to explore how a woman's perception of her family identity in relation to her SLE is shaped by narrative sense-making (i.e. SLE narrative plot lines) and family communication, I turn to McAdams' (1993) conceptualization of the personal myth. For McAdams (1993), personal identity is a personal myth that is narratively constructed in

collaboration with the social world in order to make sense of our lives and the lives of others. Building from this concept of collaboration between the self and the social world, I extend the concept of personal myth to conceptualize a *family myth* representing an individual's perception of their family's identity in relation to their illness. In other words, a family myth in illness is a reflection of how an ill individual perceives her family in light of her illness experience (e.g., supportive or unsupportive). Just as personal identities, or myths, are narratively constructed in collaboration with the social world to make sense of ours and others' lives, family identities, or myths, are narratively constructed in collaboration with the social world, particularly our family members, to make sense of our lives *in relation to our families*. Thus, family communication (i.e. collaboration with the social world) and SLE narrative plot lines (i.e. narrative constructions) are central to the way an individual perceives their families in relation to their illness (i.e. family myths). Given that an individual's perception of their family's supportiveness in relation to their illness has implications for the management of chronic illness (Rosland et al., 2012), it is vital that we explore family myths in SLE. Thus, the third research question is aimed at integrating the thematic analysis from Study 1 into the proposed Study 2 by exploring how family communication and narrative sense-making work together to form an SLE family myth variable.

RQ3: How do SLE narrative plot lines and family communication behaviors that emerged in the thematic analysis combine to inform the development of an SLE family myth variable?

CHAPTER 3

METHODS STUDY 1

This qualitative study is aimed at understanding the common experiences of women with systemic lupus (Creswell, 2013). It is grounded in what communication scholars refer to as the interpretive paradigm (Braithwaite & Schrodt, 2015) and what mixed methodologists refer to as a social constructivist paradigm (Creswell, 2013). The interpretive paradigm assumes that human action is purposive and driven by the social web of meanings in which actors are situated (Baxter & Babbie, 2004). The social constructivist paradigm assumes the existence of multiple realities that are co-constructed in communication (Creswell, 2013). Although the terminology differs, these two approaches are commensurate in their emphasis on the constitutive nature of human communication and the importance of understanding the local context in which human action is situated. For the dissertation, because it is a mixed methods study that emphasizes communication processes as constitutive, I use the term social constructivist. This move enables me to both situate this study within communication literature that positions communication as constitutive as well as remain true to the mixed methodological orientation of this study. Given that SLE is not well understood and has been given minimal attention in the social sciences, it was necessary to first understand what the specific experiences are of women with SLE in an interview study. This first exploration can then inform additional population specific research as proposed in Study 2.

Participants and Recruitment

After securing IRB approval, participants were recruited from online support groups, the Lupus Foundation of America, referrals from physicians treating women with SLE, and from my personal network using snowball sampling techniques. Snowball sampling is particularly useful when trying to access populations that are not easily identifiable (Noy, 2006), like those struggling with SLE.

The sample for the present study included 28 women ranging in age from 36 to 74 ($M = 57$ $SD = 11.22$). The majority of participants ($n = 24$, 89%) identified as Caucasian. One participant (4%) identified as a mixture between African American and African Indian, one (4%) identified as Mexican, one (4%) identified as Italian American, and another (4%) identified as Jewish American. Participants varied in the number of years since symptoms began, with one reporting “since childhood” and the remaining 27 participants ranging between 4 and 60 years ago ($M = 22.41$ $SD = 13.54$). Similarly, they varied in their time since diagnosis, with diagnosis ranging from between 1.5 and 33 years ago ($M = 16.32$ $SD = 11.56$). On the whole, these participants were well educated, having all earned at least a high school diploma, several holding college degrees and a few with graduate degrees. Specifically, 8 (29%) participants reported high school as their highest level of education, 3 (10%) reported having earned an associate’s degree, 7 (25%) indicated they had earned a bachelor’s degree, 9 (32%) held a graduate degree of some kind (i.e. M.A., J.D., Ph.D., or M.D.). 1 (4%) participant reported having graduated from a cosmetology school. The majority of these participants were married, with 20 (71%) reporting that they are currently married, 1 (4%) indicating she was widowed, 4 (14%) reporting being divorced, and 3 (11%) indicating they are single. 24 (86%) of

these participants reported having children, and 4 (14%) participants indicated that they did not have children.

In order to participate, participants were required to have been diagnosed by a medical physician with systemic lupus for at least one year. SLE is a disease that can take a significant amount of time to identify and diagnose, and being given a diagnosis is a significant part of the illness experience (Charmaz, 2006). The time prior to diagnosis is often experienced as confusing and without medical legitimation, but the time at and following diagnosis tends to be more cohesive with the medical legitimation of the illness in the dominant biomedical narrative of illness (Harter et al, 2010; Japp & Japp, 2005) provided by an official diagnosis (Mendleson, 2009). Though seemingly arbitrary, requiring participants to have had a diagnosis for at least 12 months provided space for a retrospective reflection on all significant elements of their illness experience given the significance of diagnosis in making sense of the illness experience.

Data Collection

In Study 1, I conducted the 28 semi-structured interviews, or interviews that are guided by an interview protocol aimed at prompting the interviewee to talk in detail about the topics of interest (Rubin & Rubin, 2012). Given that the interview is an interpersonal situation (Kvale & Brinkmann, 2009) and, as such, it facilitates a partnership between the interviewer and interviewee in the co-production of knowledge as conversational partners (Rubin & Rubin, 2012). Interviews are dependent on this “human-to-human connection” (Fontana & Frey, 2000, p. 654), positioning the researcher and the respondent as equals in the research process. The interview places primacy on the knowledge of the interviewee, and de-emphasizes the primacy of the academy in knowledge production. Thus, the use of semi-structured interviews enabled a focus on the participants’ meanings and understanding of SLE and family communication rather than focusing on the researcher’s ideas about these topics (Kvale & Brinkman, 2009). In other words, the semi-structured nature of the interviews provided space for participants to express what was important to them in response to the questions and allowed the interviewer to follow up on emergent ideas and topics. Given my intent in this study to explore the participants’ meanings and understanding of SLE and family communication, semi-structured interviews were an ideal method of collecting data.

The interviews were conducted primarily over the phone based on interviewee preference and to manage the challenges presented by geographic distance. The interview protocol used in this study was pre-tested on two participants to ensure its ability to answer the research questions under investigation (see Appendix A for the full interview protocol). In an effort to understand the illness narratives at play in the sense-making of

the participants, I asked them to tell me the story of their illness. I followed that with questions about how they talked about the illness in their families, letting them define family (either nuclear or family of origin) as they responded to the questions in order to let the participants indicate what type of family communication was important to them. The interview ended with an opportunity for the participants to add anything they deemed important that the interview did not uncover.

Data Analysis

The 28 interviews included in this analysis lasted an average of 43 minutes ($M = 43.23$, $SD = 14.01$). They were transcribed, resulting in 279 pages of single-spaced data. All participant names were changed to pseudonyms during the transcription process. All capital letters were used to indicate when participants placed emphasis on words or phrases. Nonverbal communication, such as crying or laughter, was indicated in parentheses. In order to identify the transcript from which the exemplars were derived, each quote was followed by the pseudonym for the corresponding participant. Because MAXQDA, the qualitative data analysis software use for this data analysis, numbers blocks of texts rather than individual lines of text, each pseudonym was followed with the corresponding MAXQDA text block number in which it appeared rather than with the more traditional line number (e.g., *Nicole*, *MAXQDA 10*).

Coding

The initial analysis of research question one involved analyzing participants' responses to the question "Can you tell me your illness story?" I found that the stories of illness presented by the participants at the start of the interview were medicalized explanations of their illness. In other words, when prompted to tell their stories of illness,

all of the participants reported a timeline of symptomatology, treatments, and treatment outcomes absent their psychosocial experience with the illness over time. This is not surprising given that the medical narrative trumps all other narratives of illness: the core social expectation of illness is to surrender yourself to the care of a physician whose story of your illness becomes dominant and is the story against which all other stories of illness are judged (Frank, 1995, 2013). Thus, when prompted to tell me their story of SLE, these women immediately recited a chronological medical history. Despite this, the whole interview was characterized by considerably richer meaning-making relevant to the research question posed. Thus, to answer research question one in a way that reflected the participant experience of the illness, and similar to Frank's (2013) methods for identifying illness narrative types, I opted to analyze both the story and interview responses to see what illness narrative types and tone animated the descriptions and stories about the illness experience offered throughout the interview.

In analyzing all the coded data for Research Questions 1 and 2, I used MAXQDA, a qualitative data analysis software designed to help the researcher explicate and organize codes and themes within the data. Using this software, I first identified themes and sub-themes (Braun & Clark, 2006) through a process of constant comparison (Corbin & Strauss, 2008) using Owen's (1984) criteria for repetitiveness (similar ideas), recurrence (same words or phrases) and forcefulness (vocal emphasis). I recorded the MAXQDA text block numbers of relevant interviewee passages (Smith, 1995) for each theme identified in the data. As I reviewed and analyzed these data, I defined and refined themes (Braun & Clark, 2006) comparing each identified theme against the concepts

identified in the data so that I could be sure the themes I identified represent the essence of the data (Braun & Clark, 2006; Smith, 1995).

This analysis resulted in six SLE narrative plot lines characterized by a combination of Frank's (2013) illness narrative types and McAdams' (1993) narrative tone (i.e. redemptive restitution, ambivalent life-as-normal, etc.) and four key family communication behaviors (i.e. avoidance, openness, confirmation, and disconfirmation) in answer of RQ1 and RQ2, respectively. These findings are presented in Chapter 4.

In the analysis of these data, it became clear that, as expected, Frank's typology of illness narratives and McAdams' conceptualization of tone worked well together as a framework for capturing the underlying plot, or illness narrative plot line that emerged in the interviews. Thus, the interviews were initially deductively coded in their entirety using Frank's (2013) six illness narrative types (i.e., restitution, chaos, quest, life-as-normal, broken, and borrowed) as well as McAdams (1993) narrative tone (i.e. redemptive, contaminated, ambivalent). Illness narrative types were identified in these data using Frank's (2013) in depth description of each illness narrative type as presented in the rationale. According to Frank (1995, 2013), an illness is characterized by each of the illness narrative types over the course of an illness, though different types are emphasized at different points in the illness. Given this, when coding the transcripts for illness narrative plot lines, I first coded for recurrent themes of a particular illness narrative type, recognizing that other illness types may also be present. Thus, the coded transcripts represent the illness narrative type that is most prominently represented in the transcript.

Analysis of SLE Narrative Plotlines

The analysis of narrative plot lines included a deductive analysis of narrative type using Frank's (2013) typology of illness narrative types and an analysis of narrative tone (McAdams, 1993). Two coders trained in narrative theorizing and qualitative data analysis read through the first four transcripts individually, coding them for narrative type and tone. Specifically, each coder individually identified which of Frank's (2013) narrative types were most predominantly reflected in each transcript, and whether or not the transcript reflected an overall redemptive, contaminated, or ambivalent tone. The coders then came together in discussion and concurred on the coding of narrative type and tone for the first four transcripts.

More specifically, narratives were coded as *restitution* when there emerged a recurrent theme of statements that reflected a focus on restoration to health and/or to life before the illness (e.g., *Every time something comes up I hope that it's something treatable and curable and we've just been missing it for 20 years-Kara*). If the codes for a transcript reflected a focus on framing the illness and/or the associated suffering as somehow improving their sense of self, purpose, or life (e.g., *And we can try to live a new normal, it will never be the way it was, but it's the new normal-Bertha*), it was coded as a *quest* narrative type. If the codes of the transcript reflected an absence of order or a focus on just getting through each day as more and more complications arise (i.e. *WOW, can all this crap be really happening to me-Kaitlin*), it was coded as having a theme of *chaos*. If the codes identified in the transcript reflected that life continued on as normal despite the illness, it was coded as *life-as-normal* (i.e. *Lupus is part of my life, it was, you know, a disorder that I had that I was dealing with and that I was always going to deal with-*

Jodi). There was no evidence of broken or borrowed narrative types in these data. Each interview was assigned one illness narrative code.

After determining the type of illness narrative that animated the interview, I focused on an analysis of the tone. The analysis of narrative tone was gestalt in nature, relying on the overall read of the transcript to see if it revealed an overall positive (redemptive), negative (contaminated), or neutral (ambivalent) orientation to the illness. Specifically, for this analysis, I sought to categorize each transcript according to the presence or absence of what McAdams (1993) referred to as dispositional optimism (the expectation for good outcomes). Thus, I determined that the narrative tone was redemptive when the overall read of a particular transcript explicitly or implicitly revealed an expectation for a positive outcome of the illness, whether that was a cure, symptom control, or an emphasis on the positive impact of the illness experience itself (e.g., *hopefully we will get ahead at some point and I will go to back to work and get off the meds-Bertha*). I determined that the tone was contaminated when the overall read of a transcript described an experience tainted by the ill-effects of the struggle and/or explicitly or implicitly indicated an expectation for things to get worse in their experience (i.e. *I've lost control of everything in my life. I have no control over anything right now, this disease is controlling me-Amber*). Finally, I determined the tone to be ambivalent in the absence of explicit evaluative statements and/or if the transcript did not reveal an overall positive or negative orientation to the illness.

Analysis of Family Communication

Another purpose of this study was to identify how women with SLE characterize their family communication. Thus, to answer the Research Question 2, the data from the

interviews concerning communication behaviors in the family were inductively coded, identifying communication behaviors in the family that the participants indicated were salient to their experience with SLE. Specifically, two coders read through the first four interview transcripts and individually engaged in open coding, breaking the data apart and delineating theoretical concepts that represented blocks of data (Corbin & Strauss, 2008). Each coder was trained in narrative theorizing and qualitative data analysis. The coders came together and discussed the themes that emerged in the process of open coding and together conducted axial coding whereby they related the emergent concepts and codes to one another (Corbin & Strauss, 2008). The coders concurred on the initial emergent codes from their open and axial coding of four of the transcripts; these codes served as a guide in subsequent analyses. Codes were then grouped into higher level categories, or themes, based on shared properties (Corbin & Strauss, 2008). This process ultimately lead to the identification of four main communication behaviors characterizing participants' perceptions of their family communication (avoidance, openness, confirmation and disconfirmation) and are presented in Chapter 4.

In order to further ensure the validity of the results, I conducted member checks. Member checks are designed to provide a summation of findings to key participants so that they can review them and confirm that the findings reflect their experiences accurately (Creswell & Plano Clark, 2011). Although member checks are often conducted in person or over the phone (Corbin & Strauss, 2008), many of the participants in this study asked for a written summation of the findings. Thus, given this and the fact that my IRB approval did not include a follow-up call, I conducted member checks by sending a two and a half page summation of the distilled SLE narrative plot lines and the

four primary communicative behaviors to seventeen of the participants, asking that they carefully review the findings to ensure that the reported findings resonated with their SLE experience in their family. I solicited their written feedback to ensure the findings of this study reflected their experience accurately. I received a total of six responses (35% response rate), all of which confirmed the findings resonated with their experiences of family communication and SLE.

Cross Case Data Matrix Analysis

Research Question 3 asked if/how family communication and SLE narrative plot lines work together to shape an SLE family myth. This represents the integration stage of this exploratory sequential mixed methods research design (Creswell, 2015). Integration refers to the process of bringing qualitative and quantitative results together in order to attain a more comprehensive understanding of the phenomena under study (Creswell, 2015). Thus, in order to answer Research Question 3 and build explicitly from the qualitative analysis in Study 1 as I move into Study 2, I developed a cross case data matrix (Miles, Huberman, & Saldana, 2014) to compare each individual participant across the emergent SLE narrative plot lines and family communication behaviors. A cross case comparison of qualitative data is an analysis that compares similarities and distinctions across cases and can be used in conjunction with thematic analysis to increase the transferability of the findings to other contexts (Miles et al., 2014). Although generalizability is not a goal for qualitative research (Braithwaite, Abetz, & Moore, 2014), this analytic move facilitates the integration of the themes identified in the qualitative analysis into the quantitative research design by examining whether or not cases can be categorized according to emergent themes. To illustrate, for this analysis,

each participant was treated as a single case. Each case was then coded for its primary narrative plotline and dominant theme in family communication, such that each case had two codes. In order to answer Research Question 3, each case was placed on a matrix and their codes were examined to see if the SLE narrative plot lines and the family communication behaviors cluster together in meaningful ways to describe specific SLE family myths (see Koenig Kellas, LeClair-Underberg, & Lamb-Normand, 2008 for a similar method). The emergent SLE family myths, then, represent the interplay between narrative sense-making and family communication in SLE.

CHAPTER 4

STUDY 1 RESULTS

Research Question 1 asked what narrative plotlines characterize women's SLE experience. Results of the deductive analyses indicate six SLE narrative plot lines as characterized by Frank's (2013) illness narratives and McAdams' (1993) narrative tone clearly emerged and animated the women's articulation of their illness experience, including ambivalent life-as-normal, ambivalent chaos, ambivalent quest, contaminated life-as-normal, contaminated restitution, and redemptive quest. Research Question 2 asked how women with SLE describe their family communication. Results of the inductive analysis indicate four key family communicative behaviors in SLE, including avoidance, openness, confirmation, and disconfirmation. Thus, I begin the discussion of results of the findings related to identifying the illness narrative plot lines within these data, followed by a discussion of the four key family communicative behaviors.

SLE Narrative Plot Lines

Research Question 1 asked what illness narrative plot lines as constituted by Frank's (2013) illness narrative types and McAdams (1993) narrative tone characterize women's experience with SLE. In analyzing these data, it was clear that Frank's (2013) illness narratives were applicable in this population for this disease context, with four of his six proposed narrative types emerging in the data (restitution narrative, the quest narrative, the chaos narrative, and the life as normal narrative). As expected, each of the narrative types that emerged had a distinct narrative tone that was captured by McAdam's (1993) concept of narrative tone. Thus, the final analysis of research question one resulted in six SLE narrative plot lines constituted by Frank's illness narrative types and

McAdam's affective tone. These include the following plotlines: ambivalent life-as-normal, ambivalent chaos, ambivalent quest, contaminated life-as-normal, contaminated restitution, and redemptive quest. They are presented in the order of frequency beginning with the most often-coded narrative plot line.

Ambivalent Life-As-Normal Narrative Plot Line

Ten (35%) of the twenty eight participants demonstrated an *ambivalent life-as-normal narrative plot line*. This SLE narrative plot line is characterized by a desire to preserve normalcy in the family, though that sense of “normalcy” may look quite different from family to family and this emphasis on normalcy is not explicitly positive or negative, it is simply a matter-of-fact expression of the way things are with SLE. This narrative plot line can be characterized by an acceptance of the new normal of lupus. Though they may recall chaotic periods of their illness, these women have accepted that the illness is unpredictable and, while they do not articulate an anticipation of positive or negative outcomes (and are thus, ambivalent), they do articulate a matter-of-fact acceptance of the unpredictability of the disease:

I mean I just never knew what it was going to throw my way. And over time I thought, well, I'm resilient I'll just have to role with whatever comes (laugh). But, you know that was a long path (Nicole, MAXQDA 10).

Kara further exemplifies how an acceptance of SLE and its implications characterizes the ambivalent life-as-normal narrative plot line:

I mean my kids have grown up with it my daughter was in middle school and my son was in middle school as well when I got really sick. My youngest was only 5 at the time. But he spent his Kindergarten year with me pretty much in bed and

not able to breathe and his brother and sister helping him with homework and doing that kind of stuff. They're great kids, they pulled together and they have a pretty good grasp on what's going on. Basically it sums up to I'm always gonna have pain. Lupus is never going to go away. And we just have to work around it (Kara, MAXQDA 26).

Finally, some participants explained a desire to protect their family members' sense of normalcy, and, in these situations, the ambivalent life-as-normal plot line is characterized by a desire to protect others in the family from the implications of the illness. For example, Tara explains how she avoids talking about her SLE in order to protect her daughter from worry:

Well I don't want my daughter to worry, so I pull back a little bit for her. She's just moved to Australia, so she went to college there so she just moved back and married her long term sweetheart and they're trying to get pregnant and I don't think the stress will be good for her, so now I'm holding back. So I don't stress her, so I'm holding back right or wrong. So it's what I'm judging is for her best interest (Tara, MAXQDA 26).

In sum, the ambivalent life-as-normal narrative plot line is characterized by the contextualization of illness into everyday life in a way that these women felt preserved normalcy as they perceived it within their particular family. The underlying theme in this plot line is an acceptance of SLE and a desire to achieve or maintain what participants perceived to be a "normal" family life.

Ambivalent Chaos Narrative Plot Line

Six (21%) of the twenty eight participants exhibited the *ambivalent chaos narrative plot line* as dominant in their articulation of their illness experience. In Frank's (1995, 2013) chaos narrative, there is an absence of narrative order and reflection. In fact, he refers to it as an anti-narrative in that it is told perpetually in the present with little focus on the present or the future. The fact that these individuals articulated their experience in terms of the past and present indicate they were not *purely* chaotic. However, Frank (1995, 2013) asserts that all narrative types are present in an individual's illness experience and the focus of this analysis was on identifying which narrative type was most *prevalent*. Thus, though those participants for whom the ambivalent chaos narrative plot line was most prevalent may have also exhibited elements of the other narrative types as outlined by Frank (2013), the features of the chaotic narrative type were most prevalent. Events in this narrative are often presented in a disorganized and often disconnected manner, though remain clearly focused on an over-determination of difficulty.

In the ambivalent chaos narrative plot line, there appears to be very little sense-making occurring in the midst of continued complications due to a focus on the struggles of the disease. Thus, the ambivalent chaos narrative plot line is characterized by an absence of order, a focus on the daily struggles of the disease, an over-determination of difficulty, and there is not implicit or explicit expectation for positive or negative outcomes. In Frank's (1995, 2013) chaos narrative type, there is little attention paid to the future given this focus on the present difficulty. Thus, it is not surprising that these narratives all had an ambivalent tone, with no clearly stated expectation for positive or negative outcomes.

The sense of disorder that characterizes this SLE narrative plot line is clearly exemplified by how Amy presented her story of illness. She jumped between detailed discussions of the physical and mental chaos of her disease:

So I have SLE lupus with the complication of vasculitis which means your capillaries tend to get enflamed. Any way he overdosed me with prednisone and when I would call him and say this is too much it made my metabolism go so high that I was taking down for three weeks, and I was bouncing off the walls. Essentially, it made me manic. And I kept calling his office and couldn't ever talk to him or his nurse. I think I did get one reply from his nurse where she said the doctor says you must take this medication or you're going to die. And I was working at kind of alternative medicine and I had gone by there and they told me I had to leave because I was making them nervous because my energy was so frantic. And I called my sister whose a nurse in Texas and I said, he won't talk to me, I'm bouncing off the walls, my brain is shorting out, I was losing time, I said what am I gonna do? And she said call your PCP and so I did that and he said you need to check yourself into the ER so I went into the local hospital in Oregon and so I went in with medically induced psychosis. Because I really was going into a fog and like I would put my food out and I'd come back later and I hadn't eaten it and I'd put my medication out and would come back later and it wouldn't be eaten. And one of my girlfriends was helping me out and called my family. I went into the psych unit where they reduced my prednisone. It was a wonderful program where you get counseling and all this and I went in there and was there over a weekend getting stabilized (Amy, MAXQDA 4).

This excerpt from Amy's transcript exemplifies the flow of a chaos narrative as it is represents "one thing after another". Her presentation of the illness experience was disorganized and chaotic in its telling, included hospitalizations and illnesses and events that seemed disconnected. In the ambivalent chaos narrative plot line, the focus is on the daily complications and struggle associated with the illness. Kaitlin explains:

So, you know, it's like I sometimes question myself, it's like WOW, can all this crap be really happening to me and I think no I'm not that kind of person, I'm a very strong person I'm not just gonna let something take over my mind. And but sometimes you do, I mean, I do, as a lupus patient I'm thinking man, am I really a hypochondriac, but everything's so real. And then, I was having muscle issues I notice that my muscles in my thighs were getting weaker, so I would do a biopsy and it was determined that it was kind of inconclusive. They thought maybe I had polymyositis. It's a rare autoimmune disease where the body attacks the muscles. Which is basically what lupus does, your body attacks whatever it wants. Whatever organ it wants. And or, they said it could be caused from long term steroid use. Well, you know, what are you gonna do, because I need the steroids for my lupus. Right now I'm just waiting and wondering (Kaitlin, MAXQDA 4).

Kaitlin's explanation of just waiting and wondering what will happen next with her illness also demonstrates the perpetual sense of being in the present that characterizes Frank's (1995, 2013) chaos narrative as she waits and wonders what the next complication will be in her illness experience. The struggle could be relational, physical, or mental. Jill explains how her physical struggle with the disease is continuous and unpredictable:

Well, I tell people, um, pain is the background music of my life. It's always there. It never goes away. I hurt all the time, Joint pain. If it moves it hurts. I've had both my knees replaced. It went to both my knee joints. So I have artificial knees now. I don't have much energy. I wake up exhausted and get more tired as the day goes on. I have good days and I have bad days. A good day I can get out of bed. A bad day I lay in bed crying. (Laugh). It's just one of those things. The pain medication no longer controls the pain. I'm on massive amounts of narcotics. And it doesn't take it away. I can tell you what the weathers gonna be 2 days in advance. When the barometric pressure changes I'm in agony. It hurts so bad. It's just, you know. I have to limit what I can do I can't make plans ahead of time because I never know how I'm going to feel (Jill, MAXQDA 18).

The chaos narrative is also characterized by what Frank (1995, 2013) refers to as an “over-determination” of difficulty. In essence, in this narrative type, everything is seen as difficult. Kaitlin explains how her difficulties with SLE transcend her financial and relational life:

And my doctor said that this was gonna go in the medical journal because it was a new side effect. Yeah. That was not good. So you know with lupus you have all kinds of crazy stuff. And with all that crazy stuff comes mounting doctor's bills which are never ending if your lupus doesn't go into remission. And so I'll tell you what to try to stay positive and you know, it's hard, it's just really hard to stay positive through all that (Kaitlin, MAXQDA 4).

In sum, the ambivalent chaos narrative plot line is defined as being predominantly disorganized, a focus on the daily struggle and hardships associated with SLE, an over-

determination of difficulty in that everything is presented as difficult, and is lived primarily in the present with little reference to the past and no reference to the future. Despite a focus on difficulty, this is ambivalent in nature because it is characterized by limited sense-making about SLE and thus, there is no implicit or explicit expression of expectations for a positive or negative outcome with the disease.

Ambivalent Quest Narrative Plot Line

Four (14%) of the twenty eight participants most prominently demonstrated the *ambivalent quest narrative plot line*. The *ambivalent quest narrative plot line* is a characterized by a matter-of-fact willingness to meet the illness head on, and an acceptance of both the suffering and the mark, or change, caused by the illness. The mark of suffering caused by SLE is perceived as beneficial and it is used in service of others, allowing these women to become everyday heroes through their suffering (Frank, 1995, 2013). Though, in accordance with Frank's (1995, 2013) quest narrative, the change that has already occurred due to the illness is itself perceived to be positive, there is no expressed expectation of future positive (or negative) outcomes of the illness experience which is why these experiences were also coded as ambivalent.

In this illness narrative plot line, the women and their families accepted that SLE had changed their lives and they used their experience to benefit others in their daily lives. There is no expressed expectation that their illness experience is being used for the benefit of others, however, they are taking action to do just that. Shannon explains how, through her suffering, she became the hero as an SLE support group leader who provides group members and their families with copies of The Spoon Theory, a metaphor to help people understand the fatigue associated with the illness:

I usually have at least 20 copies of it with me at my group that I facilitate with the Lupus Foundation of Florida is every month and I bring that with me and I make sure if anybody's new they get it and I also invite family members to the meeting and lot of people to bring family members and I make sure they get a copy and it really explains the fatigue part of lupus really well (Shannon, MAXQDA 30).

As a physician, Monica is able to use her experience as an SLE patient to counsel her patients and their families on how best to manage the SLE:

And just telling them that you're gonna have your ups and your downs. You know it's some days are gonna be great and it's it's but, you can't kind of count on that either. And you have to figure out what works for you, what doesn't. And go with that. Because I try to be somewhat cautious because what works for me may not be appropriate with their given circumstances. But you know really listening to themselves and just I REALLY, more than anything, I strongly recommend that they build up that support system (Monica, MAXQDA 42).

In sum, the ambivalent quest narrative type is characterized by meeting the illness head on and not only accepting the change imposed by the illness, but positioning the change, or mark of the illness, as an important and useful transition. Further, the women whose experience with SLE exhibited this narrative plot line engage in opportunities within their daily lives to assist others in their struggle with SLE.

Contaminated Life-As-Normal Narrative Plot Line

Four (14%) of the twenty eight participants exhibited the contaminated life-as-normal narrative type as dominant in their articulation of their SLE experience. *The contaminated life as normal narrative plot line* is characterized by a desire to achieve or

maintain a sense of normalcy, but contrary to the ambivalent life-as-normal plot line, women whose experience was characterized by the contaminated life-as-normal plot line, perceived the existence of relational tension in their families about what normal should look like in the face of SLE. Thus, in this narrative plot line, women with SLE perceived that they attempted to live their lives “normally” despite the experience of SLE. However, contaminated life-as-normal is characterized by a felt family tension between what normal should look like in the face of SLE. This tension may manifest as a perception that family members desire and expect a return to the pre-illness normal, while participants recognized that this return was not possible or, it may manifest in just the opposite way. Evelyn explains how she and her husband have different ideas about how to live with SLE, and these differences create an uncomfortable tension for her:

At one point, at one point, my husband did say. I was searching and searching and searching for something to help me. And he told me to stop. He said this is what you have, it's not gonna get better and deal with it. And this was five years ago. So I was 46 and I said, I'm too young, and I gotta do this, nobody else will help me, so, it was very unsettling (Evelyn, MAXQDA 12).

Thus, this narrative plot line is characterized by avoidance and a feeling of being unsupported within the family (Rosland et al., 2012). Melissa explains how she avoids talking about it because she perceives that her family prefers not to hear about the disease and its effects: “*But I just think I probably don't talk about it they're just tired of hearing it*” (Melissa, MAXQDA 24). In addition to a perceived absence of social support, Melissa's explanation exemplifies how avoidance in this narrative plot line may be driven by a desire to protect existing relationships.

When the kids come over, when we do get the chance to get together for dinner, my son lives in Boston, my daughter lives about an hour away. And my younger son does more traveling. So when we do get time together, I don't talk about lupus anymore. They know I have it and I think it's just not fun. You know? I do say sometimes especially to my husband, you know look I can't do that I just feel so awful (Melissa, MAXQDA 24).

Dierdre exemplifies how the normal she lives with every day is different than her family members' idea of life as normal with lupus:

Yes, and I've had experiences being invalidated or minimized. The symptoms being minimized. And you know, maybe the frustration on the part of others. It's not easy to describe to someone. It's not easy to describe to someone what it is. It's a disease LADEN with complexities and symptomology that mimics other things that have to be ruled out. But at the end of the day leaves me feeling unwell so often that I don't want to talk about with people because I don't want them to feel sorry for me. So, you know what I'm just gonna say I'm okay (Dierdre, MAXQDA 46).

Thus, this SLE narrative plot line is characterized by a desire to achieve/maintain normalcy and a felt tension between family members about what constitutes normal in the face of managing SLE. Women making sense of SLE according to this narrative plot line have an overarching sense that they and their family members have different ideas about what life should look like with SLE.

Contaminated Restitution Narrative Plot Line

Two (7%) of the twenty-eight participants demonstrated evidence of a *contaminated restitution narrative plot line* in their explanation of their illness experience. This narrative plot line was characterized by struggle for improvement in the disease despite an expectation for negative outcomes. In contaminated restitution, participants continue to strive toward some kind of cure or improvement despite a clear sense that improvement is not likely. These women are fighting their way through to try to survive the disease, holding onto hope for restoration to the life they knew prior to the illness, even as they understand that restitution is not possible. Amber explains:

So it changed my life completely. I had to quit working, I had to go on disability which was really hard for me. It still is hard. I keep thinking I might be able to go back, but I know I can't physically do it. So it's been life altering (Amber, MAXQDA 7).

Thus, these women continue to strive for restitution and resist allowing the illness to change their lives, although they appear to understand that restoration is not possible. After describing herself as a driven person and detailing her extensive schooling and the career successes that she's had while managing severe symptoms of SLE, Stephanie explains how difficult it is for her to understand why she doesn't have the same drive she had before SLE:

You know there's only so much energy I have at the beginning of the day and really sometimes I want to work and I can't work and I get up and sit at the computer and a whole day goes by and I haven't done anything. And I'm not having pains that day, but I'm just tired. That's the hardest fatigue because you can't see the fatigue, there's nothing to test for fatigue. And so that's the hardest

thing and maybe the reason it's hard for me to communicate that as well is because I have a fear of being seen as lazy, just un-motivated. Because I've never been that way before, it's just REALLY really hard for me (Stephanie, MAXQDA 22).

She goes on to explain that it is this part of her disease that is the hardest for her to understand as she manages it in her daily life:

I think that the most difficult thing that I don't discuss is the psychological. Just being depressed and I mean there are days I just shut out people. Even though I'm trying, just not understanding why I don't have that focus that I usually have that fuels my drive. That's the hardest part for me to deal with and that's the hardest part for me to communicate (Stephanie, MAXQDA 20).

The fight for restitution and against the changes associated with the illness that characterize this illness narrative plot line may well exacerbate the compounding of physical and mental complications associated with chronic illness (Canary, 2008).

In this narrative plot line, women avoid talking about the disease in order to restore the sense of control they had over their lives pre-illness. Amber explains:

Um, because I'd rather not talk about it. I feel like I don't want it to consume my whole life. And it has in so many ways and I feel like this is the only control I have left is to not talk about it all the time (Amber, MAXQDA 33).

In this excerpt, Amber demonstrates how she chooses not to discuss the illness in her family in order to re-gain some control in her life, reminiscent of the restitution's narrative focus on restoration (Frank, 1995, 2013) as she attempts to restore some part of her life to her pre-illness sense of normal. Thus, the contaminated restitution narrative

type is characterized by a focus on restoration even as the individual continues to suffer chronic complications. It is further characterized by a tendency to avoid discussing the illness in an attempt to regain control over some part of the experience.

Redemptive Quest Narrative Plot Line

Two (7%) of the twenty eight participants demonstrated the redemptive quest narrative plot line. The *redemptive quest narrative* plot line is a quest narrative in which the participants explicitly use their struggle with SLE to enact social change with an expectation that things will get better because of their suffering in illness. This is reminiscent of Frank's (2013) manifesto within the quest narrative in that these women are using what they have learned in their suffering to change how others experience the disease, often demanding change through their educational efforts Shannon explains how she communicates within her family and her support group to help others deal with their disease and educate patients and family members of patients. Bertha has used her suffering in SLE to educate political leaders about chronic illness in general and autoimmune diseases in particular.

A good conversation was with senior staffer at the White House, and I brought my family to Washington DC and sat down and went to the white house to educate them, and you tell them what chronic illness is like and autoimmune disorders to show them what families go through. And it was a positive experience for my family because my kids felt like they were doing something actionable, and my husband felt like he was doing something that was actionable, I felt like I was doing something that was actionable and we felt like we were taking control (Bertha, MAXQDA 45).

Elise used her experiences to publish a book aimed at educating patients with systemic lupus about the way the disease impacts their lives and goes on speaking engagements to educate patients, families and medical professionals about systemic lupus:

Yes, and my husband accompanies me and on speaking engagements when he can, when he can he talks like I do my presentation, I've done it several times at MUFC for family and friends of lupus and I usually get him to give his perspective and answer questions and he stays until I'm on it. He will read things and he just really tries to understand (Elise, MAXQDA 34).

Thus, the redemptive quest narrative type is also characterized by a willingness to meet the illness head on and an acceptance of the changes brought on by the illness as an important and meaningful life transition. However, what differentiates it from an ambivalent quest narrative is the desire to use their illness struggle to enact social change regarding SLE beyond her daily interactions (i.e. lobby for SLE awareness or author and publish a book about living with SLE).

Summary

Distinct SLE narrative plot lines comprised of a combination of illness narrative types and narrative tone clearly emerged in these data. These plot lines differed in their primary focus (e.g., life-as-normal plot lines focused on normality, restitution focused on restoration, quest focused on making suffering meaningful, and chaos was focused on the struggle of the disease). They differed further in terms of their tone, or whether or not there was an expectation for a positive or negative outcome of the illness. Now that I have summarized the illness narrative types that emerged in these data in response to Research Question 1, I will move onto a discussion of the family communication that

characterized these women's experiences with SLE. I will first focus on the four communicative behaviors that emerged and then will move to a discussion of the family themes that emerged in the data. I will then talk about the interplay between the family themes and the individual narrative types.

Family Communication in SLE

Research Question 2 asked how women with SLE characterized their family communication. Four key family communication behaviors emerged in these data: avoidance, openness, confirmation, and disconfirmation.

Avoidance

A first characterization of family communication for women with SLE was avoidance. Avoidant behavior was defined as eschewing communication specific to SLE. Consistent with previous research (e.g., Shapiro, Angus, & Davis, 1997), participants tended to avoid talking about their illness to protect themselves (i.e. to evade the emotional difficulty of the disease, to manage their identity in illness, or to regain some control over the experience) as well as to protect others (i.e. to avoid scaring or worrying loved ones). Allison explains how she relies on her family's norm of avoiding discussions about her SLE to help her maintain boundaries in her family. For example, she is unable to assist her ailing father because of the limitations of her disease, so, she offers vague explanations about why she cannot help:

And also my Dad has Alzheimer's and so in the past year, the past 10 years, I mostly just say, I'm tired, I have to rest, or I can't do that, no, it's mostly my trying to create a boundary about helping. And I also have kind of thought because it is so you know, it's just been going on for so long and it's such a

complex topic that I haven't really said and they don't ask me (Allison, MAXQDA 10).

Participants also indicated that they engaged in avoidant behavior to protect others in their family. For example, Lysa avoids talking about her SLE because she knows that it will upset them, and Kaitlin talks about protecting her parents through avoidance “*I would try not to show them my pain because you know a parent never wants their kids to hurt*” (Kaitlin, MAXQDA 8).

Participants also tended to avoid discussing SLE in order to protect their family relationships, an interesting finding particularly given the importance of family social support in managing chronic illness (Rosland et al., 2012). Lysa says:

Sometimes, I don't want to talk about it with them because I think maybe I'm talking to them too much about it. They say that's not true but I don't want them to run from the phone when I call (Lysa, MAXQDA 16).

This is an important paradox for SLE patients. Avoidant behavior aimed at protecting relationships preserves general social support so important to managing chronic illness, but threatens disease-specific social support.

Avoidant behavior was also driven by a desire to regain some sense of control in the individual's illness experience. This often manifests in a desire to emphasize important parts of the individual's life other than the illness as Laura describes:

I get tired of talking about being sick all of the time, I'd rather talk about the good things going on in my life. So I started my swimming regimen yesterday, so talking to my son yesterday I'm not talking about my disease talking about how

many laps I did in the pool. To let them see that this disease is just one part of the whole (Laura, MAXQDA 26).

In sum, avoidant behavior tended to be driven by a need for self, other, or relational protection, a desire to regain control over the disease, as well as by the perception that there exists an absence of social support in the family.

Openness

Open communication in illness has positive implications for health outcomes (Rosland et al., 2012), so it is important that open communication emerged as one prominent theme in the experience of many of these participants. Those who reported open communication about SLE indicated that this openness tended to be facilitated by the expression of true interest and concern for the participant or by a pre-existing family communication climate of openness. Thus, open communication is distinct from yet facilitated by confirming communication.

First, open communication was easier for participants to engage in when they perceived the person to whom they were speaking truly understood their struggle, because they had a similar struggle of their own. Carol explains “I also have a sister that also has an autoimmune disease, and I talk with her quite a bit about that” (*Carol, MAXQDA 22*). Tara explains that “*unless someone has a chronic illness, they really don’t understand chronic illness*” (*Tara, MAXQDA 18*).

Second, the perceived expression of sincere interest (as opposed to insincere inquiries) facilitated open communication about SLE. As Dierdre explains:

First I would have to do an assessment if anybody was really interested. Honestly, I shy away from sharing that until I have an honest ear. Because it’s a complex

disease, it presents in insidious ways, and um, so, I would be cautious about sharing my story. Because I look well, you know 85% of the time. But I'm quite ill. So that would be sort of what I would do. So there's some trepidation to start with (Dierdre, MAXQDA 34).

Third, family communication climate was an important factor in facilitating open communication about SLE. Elise explains:

Okay, I've always been close to my family of origin, I was the oldest of five girls and then a brother and I mean my mother we were always very direct and honest, I mean, I just never had to hold back in ANY way. And with my son, there was a period of time where he tended to lean more toward his father because I think his father had influenced him to say your mom its in her head and he would say things like well mom maybe if you just exercise more, and you know. But now he's learned and he is different, so, with my family, I don't have to hold back anything (Elise, MAXQDA 52).

Open communication about the illness is an important part of managing a chronic illness (Rosland et al., 2012). These data reflect that an established family climate of openness and the perception that the other person understands and is sincerely concerned about the well-being of the individual are cited by these participants as important to facilitating open communication about the disease. This implies that confirming communication and potentially perspective-taking, or behaviors that acknowledge, attend to and confirm the other (Koenig Kellas, Trees, Schrodtt, Le Clair Underberg, & Willer, 2010) are important to a sense of openness about SLE. Thus, I move to an explicit discussion of confirmation and disconfirmation as they are represented in these data.

Confirmation

Participants cited confirming communication as prevalent and significant in their experience of SLE. Confirmation conveys positive regard for the other person. Drawing from confirmation theory, Dailey (2006) explains that “confirmation is defined as the degree to which messages validate another as unique, valuable, and worthy of respect and cause individuals to value themselves more” (p. 436). The behaviors identified as confirming by participants were the communication of concern and behaviors associated with educating oneself about SLE. Concern was communicated in a variety of ways ranging from being involved in care, expressions of sincere interest in the patient’s well-being, prioritizing the relationship over the disease and its effects, and trusting the participants’ descriptions of the illness experience without question. Jodi explains how her mother confirmed her experience with SLE:

My mother was a very intelligent woman. Was interested in the medical field and was very passionate about my being sick. I think she felt responsible because they were thinking that it was genetic then and she couldn’t figure out how she had to have the pain that I was dealing with and she was very compassionate about and she talked with me a lot about it (Jodi, MAXQDA 20).

Concern was also communicated through implicit trust that the symptoms the individual is experiencing are actually occurring. Lysa explains:

Well they’re very receptive. They never question the truth about what I’m saying when I say for example well yesterday I was feeling great, but today I feel horrible. They don’t ever question that (Lysa, MAXQDA 32).

Being open to learning about the disease was another important form of confirmation of the illness experience of these participants. Monica explains:

So from the get go when I was first getting diagnosed of course, my husband and I are very close. We both researched things a lot. You know, he read an awful lot of things. Um I got involved with the Lupus foundation of Florida. And we had gotten some books on chronic disease and some simplistic explanations of lupus so my kids' actually probably know more about lupus than most first year medical students (laugh) (Monica, MAXQDA 22).

Women also experienced confirmation when family members took it upon themselves to initiate their own education about the disease, as explained by Amber when talking about her kids' attempts to learn more about her disease:

And when they looked it up on the internet, like kids do now, they were like oh my God, because they saw how horribly sick people can be with this. And I think that was kind of their aha moment (Amber, MAXQDA 31).

Thus, the two primary ways to confirm an individual's experience of SLE that emerged in these data were to communicate sincere concern for the individual's well-being as well as to be open to and/or initiate education about the disease. As clearly as confirmation emerged as a positive communicative behavior in these data, disconfirmation emerged as a negative communicative behavior. Thus, I turn next to a discussion of the themes characterizing disconfirmation.

Disconfirmation

Disconfirmation conveys negative regard for the other person. Dailey (2006) asserts that "disconfirmation denies the other as being a valid communicator and regards

the other as inferior or as an object and cause individuals to value themselves less” (p. 436). The behaviors identified as disconfirming by these participants were those that conveyed disbelief, minimization of the daily struggle, over-emphasizing SLE in the relationship (e.g., emphasizing the discrepancy between being a “normal” mother and managing the disease, disease facilitating privacy violations, and disease related over-protection), and a failure to communicate concern. The expression of disbelief, not surprisingly, emerged as an indication of disconfirmation, as articulated by Brenda:

My aunt constantly accused me of faking it and making things up to be sick over. She was at a stage she didn't believe me. In the ER they were pushing round after round of morphine and it didn't touch me. And she said you really are in pain. And I remember thinking after 35 years you have the nerve to say that to me?
(Brenda, MAXQDA 6).

Though disbelief of the existence of the disease was not uncommon, family members more commonly believed the participant had the disease, but proceeded to disconfirm the daily struggle of the disease. This often manifested as a failure to acknowledge the inherent limitations of a particular participant's manifestation of the disease, as explained by Jill:

Um, they'll ask me to do things that I'm just not capable of doing. And I'll have to say I'm sorry I just don't have the energy to do that. And I get the feeling that they think I'm slacking. That I'm just lazy and I don't want to participate (Jill, MAXQDA 24).

A second form of disconfirmation that emerged was prioritizing the disease over the person in family relationships. Rather than ignoring the disease as is detailed in the

previous themes of disconfirmation, this type of disconfirmation is characterized by an over-emphasis on the disease. This was experienced as disconfirming because it served to minimize the woman's identity in relation to her illness, positioning her as inferior because of the limitations of her disease. This manifested in three distinct ways: emphasizing the discrepancy between being a "normal" mother and managing the disease, disease-facilitating privacy violations, and disease-related over-protection. Amber explains how negotiating the interruption of "normal" motherhood was disconfirming for her:

But initially they were angry (laugh). I think they felt like they had lost, my kids especially, they felt like they had lost a mother because I'm not who I used to be? I have a 26 year old a 22 year old and a 28 year old. So they, it was you know, my daughter was still in her teens when all this started (Amber, MAXQDA 25).

The disease also facilitated privacy violations as family members felt their concern for the participants' experience with SLE afforded them access to otherwise private information. Lysa highlights how her openness in her family about SLE left her open to privacy violations as her family asked questions about her family planning. She saw these privacy violations as disconfirming her.

I think that's very important because we want to have the same privacy, I guess, right, that someone who doesn't have lupus. And even though my family and I are close, you know, some things are just private. It affects a lot of things. It affects everything basically. It affects sexuality. All those private things that might become public if you're not careful (Lysa, MAXQDA 52).

Finally, women highlighted disease-related over-protectiveness as disconfirming and another example of prioritizing SLE in family relationships. Kara explains:

I think they forget the psychological part of it. I'm still a human being. And I tell them all the time, How would you feel if you couldn't do this anymore. You're sitting there like you're feeling good and you're feeling normal and like you should be able to um, and somebody stops you. Or you know that if you do it then you're gonna feel bad. It's hard when you feel good to convince yourself not to do it because you'll feel bad. If you feel bad you're not gonna want to do it. So I try to explain those sorts of things I think they struggle more with that part of it. They say they understand but every time I do something they rush into help. So if I bend over to get the laundry, they know if I bend over I have trouble breathing, and so they'll run in and grab it, because they know that if I do that 3 times in a day, my lungs are gonna be sore and I'll be lying in bed (Kara, MAXQDA 48).

The last disconfirming behavior reported by the women in the sample was an overall failure to communicate concern for the participants. Celeste explains what the absence of concern for the disease process looks like in her relationship with her sister:

And I was telling her oh I've got to go tomorrow for another test and I'm still sore from another one. And she says "well at least you have Welfare to pay for your medical expenses because I can't even afford to go to the doctor if I need to". Laugh. And I told her. I got mad. And I said I would give ANYTHING to not be on Medicaid and to have a job where I earn a decent income and afford a better car and it's not my choice that I'm sick like this. And she didn't have anything to add to that. She's very judgmental (Celeste, MAXQDA 44).

For these women, disconfirmation in the context of lupus can be characterized as disbelief, minimization of the daily struggle, an over-emphasis of the disease (i.e. tension between being a good mother and managing disease, disease related privacy violations, and over-protectiveness), and a failure to communicate concern for the well-being of the individual.

Cross Case Data Matrix Analysis

Research Question 3 asked how the SLE narrative plot lines and family communication behaviors identified in the original thematic analysis combine to inform the development of an SLE family myth variable. In this analysis of the data, each transcript was treated as an individual case. In order to determine which family communication behaviors that emerged in the initial thematic analysis were most prevalent in each individual case, each transcript was again read in detail, this time with an eye toward which family communication behaviors were most prevalent. Ultimately, each case was determined to reflect either predominantly open or closed and either predominantly confirming or disconfirming communication. Thus, each case was assigned three different codes: (a) one dominant SLE narrative plotline, (b) either open or avoidant communication, and (c) either confirming or disconfirming communication).

Next, the cases were placed in the cross-case data matrix analysis in order to evaluate if/how the cases clustered together in meaningful ways (Miles et al., 2014). Because there was the possibility of 24 combination of codes given that this cross-case data matrix analysis was 6x2x2, I looked at the case matrix initially to see if there were conceptual groupings that would guide the analysis. I noted all the cases coded as open and confirming shared similar narrative plotlines (e.g., ambivalent life-as-normal,

redemptive quest, ambivalent quest) that were, for the most part, unique from those cases that were coded avoidant and disconfirming. In evaluating those cases coded as having avoidant and disconfirming communication, I noted another clear distinction in the narrative plotline that was coded for these cases. For example, a large sub-set of those cases that were coded avoidant and disconfirming were also coded as having the ambivalent chaos narrative plotline. A second sub-set of those coded with avoidant and disconfirming communication were also coded as having a contaminated plotline (i.e. contaminated restitution or contaminated life-as-normal). Given these initial observations about the potential for three distinct groups, I read through each of these three sets of transcripts to make sure that the grouping made sense. Thus, for the second stage of analysis, in addition to grouping all the cases with open and confirming communication together, I grouped all the cases that were categorized as having predominantly ambivalent chaos narrative plotlines together and grouped all the contaminated restitution and contaminated life-as-normal narrative plotlines into the third and final category.

Next, I re-read all of the transcripts in each group making note of similarities and distinctions among the cases within each of the three groups (Miles et al., 2014). In re-reading the transcripts according to these groups, it became clear that these participants were describing three distinct experiences of family in relation to SLE that were comprised of the interplay between narrative plotlines and family communication behaviors (i.e. three distinct SLE family myths)—a harmonious experience within the family, an experience of abandonment, and an experience that reflected a battle within the family about SLE. It was clear that these three SLE family myths encompassed each one of the cases in this analysis, though there were a few cases that, based on this stage of

analysis, needed to be re-assigned to a different SLE family myth. Thus, recognizing the fluid nature of narrative types (Frank, 1995, 2013) and sense-making in the family (Pecchioni & Keeley, 2011), as well as in evaluating the unique circumstances of specific cases, I re-assigned them to the SLE family myth that seemed to best reflect their overall experience and took another critical look at their individual case. Ultimately, the cross case data matrix analysis revealed three distinct SLE family myths (see Table 1 below), or individual's experience of family in relation to their SLE as comprised by SLE narrative plotlines and family communication. In what follows, I detail the analytic process that drove the solidification of the three SLE family myths (harmonious, battle, and abandoned). These SLE family myths are explained in order of their prevalence in these data, with the most common SLE family myth presented first and the least common presented last.

Emergence of Harmonious SLE Family Myth

Unlike the other two SLE family myths, all the cases in the harmonious SLE family myth described open and confirming family communication about SLE. Further, all the cases in this SLE family myth described either an ambivalent life-as-normal, redemptive quest, or ambivalent quest SLE narrative plotline. Though there was just one other case that described an ambivalent life-as-normal narrative plotline that was categorized in the battle SLE family myth rather than the harmonious SLE family myth (Tara, Participant 7), she also described mostly avoidant and disconfirming family communication about SLE.

Emergence of Abandoned SLE Family Myth

All of the cases in the abandoned SLE family myth described predominantly avoidant and disconfirming communication, Stephanie, described a predominantly contaminated restitution narrative plotline while the rest of the cases in the abandoned SLE family myth were ambivalent chaos. Upon closer review of the transcript, it was clear that Stephanie (Participant 9) was at a point of transition in her sense-making about SLE. She had just opened up to her family the weekend before about the difficulty of her disease, and was moving from a chaotic to restitution narrative plotline, though she was still uncertain about how her family would respond to her disclosure about her struggle. They initially were quite supportive though she was not confident that it would change her situation. In another example, Joan's SLE family myth reflected the perception of abandonment by her family overall. At the time of the interview, she was facing a life-threatening situation with her SLE and therefore, though her narrative plotline was chaotic and her communication was avoidant, her interview reflected predominantly confirming family communication as she was anticipating having to disclose the severity of her situation to her family that evening. Each of these situations was unique and represented a narrative in transition, thus I deemed it appropriate to include them in the abandoned SLE family myth

Emergence of Battle SLE Family Myth

Similarly, all of the cases grouped into the battle SLE family myth described avoidant and disconfirming family communication and had predominantly contaminated narrative plotlines. Amber's (Participant 1) narrative plotline was predominantly contaminated restitution, though she had also just disclosed her struggle with SLE to her family and had been met with disconfirming communication. Thus, the timing of this

interview may have impacted which narrative plotline emerged as most dominant. Given the similarities in her overall depiction of her family communication to the other cases that comprised the battle SLE family myth and the consistent description of avoidant and disconfirming family communication about SLE, I deemed it appropriate to include her case in this SLE family myth.

Table 1 Joint Display of Cross-Case Data Matrix Analysis

Pseudonym (Transcript number in parentheses)	SLE family myth	Narrative Plotline	Open-Avoid	Confirm-Disconfirm
SLE family myth 1				
Stephanie (9)	Abandoned	Contaminated Restitution	A	D
Amy (10)	Abandoned	Ambivalent Chaos	A	D
Betty (13)	Abandoned	Ambivalent Chaos	A	D
Kaitlin (19)	Abandoned	Ambivalent Chaos	A	D
Celeste (21)	Abandoned	Ambivalent Chaos	A	D
Jill (26)	Abandoned	Ambivalent Chaos	A	D
Joan (4)	Abandoned	Ambivalent Chaos	A	C
SLE family myth 2				
Amber (1)	Battle	Contaminated Restitution	A	D
Tara (7)	Battle	Ambivalent LAN	A	D
Evelyn (12)	Battle	Contaminated LAN	A	D
Allison (16)	Battle	Contaminated LAN	A	D
Dierdre (25)	Battle	Contaminated LAN	A	D
Melissa (30)	Battle	Contaminated LAN	A	D
SLE family myth 3				

Bertha (2)	Harmonious	Redemptive Quest	O	C
Carol (3)	Harmonious	Ambivalent LAN	O	C
Lysa (5)	Harmonious	Ambivalent LAN	O	C
Jodi (6)	Harmonious	Ambivalent LAN	O	C
Shannon (8)	Harmonious	Ambivalent Quest	O	C
Angie (11)	Harmonious	Ambivalent LAN	O	C
Laura (14)	Harmonious	Ambivalent Quest	O	C
Brenda (17)	Harmonious	Ambivalent Quest	O	C
Lexie (20)	Harmonious	Ambivalent LAN	O	C
Nicole (22)	Harmonious	Ambivalent LAN	O	C
Sarah (23)	Harmonious	Ambivalent LAN	O	C
Diana (24)	Harmonious	Ambivalent LAN	A	C
Elise (27)	Harmonious	Redemptive Quest	O	C
Kara (28)	Harmonious	Ambivalent LAN	O	C
Monica (29)	Harmonious	Ambivalent Quest	O	C

Harmonious SLE Family Myth

Fifteen of the participants (53%) in this study described a harmonious SLE family myth characterized by open communication about SLE, confirmation of the experience of SLE through the communication of concern, and the perception that family members were willing to become educated about SLE.

The family is perceived as communicating openly about the illness experience. Patients perceive that the family communicates their concern for them and that the family

embraces their attempts to educate them about their disease. The family is perceived as working with the ill family member to navigate the illness and construct a family narrative from which to make sense of this illness together.

The women that reported a harmonious SLE family myth made sense of their SLE using a quest narrative plot lines (2 redemptive quest and 4 ambivalent quest) and life-as-normal narrative plot lines (9 ambivalent life-as-normal and 1 contaminated life-as-normal). This SLE family myth was primarily characterized by open and confirming communication, with 14 of the 15 participants describing their family communication in this way. Sarah explains how her family communication about SLE was open and continuous *“I would be hard pressed to come up with ONE conversation that was particularly good or bad. Because there’s been lots of smaller conversations that have gone on”* (Sarah, MAXQDA 43). These families tended to view the disease as just another part of their experience to be discussed in everyday conversation, highlighting the importance of everyday talk in families for health (Welch Cline, 2011).

In addition to openness, confirmation was an important part of this SLE family myth. Lysa describes the importance of her family’s confirmation of her as she described symptoms that seemed difficult to believe:

I’ve always been straight open with them from the beginning and they never questioned what I was telling them. When I told them I was hearing things nobody ever said that’s not true it’s all in your head or anything like that (Lysa, MAXQDA 14)

Though one participant described her family communication as avoidant and confirming, she was clear that her avoidance was an attempt to minimize her family's focus on the disease and protect them from worry.

I don't want to worry people. I'm very very strong and some people have said to me "I can't believe your pain tolerance" or something like that. I don't know there are great things in life and you have to step toward those and try to step over those that aren't so great in your life. Yeah I don't want to worry my children by always complaining or moaning (Diana, MAXQDA 54)

Another characteristic of this SLE family myth was that these women perceived their families as communicating their sincere concern for them as they managed SLE. Participants reported that family members would articulate that they understood their experience in sincere ways. For example, Angie indicated *"And he [her spouse] said, "I really hate to see you going through this". And I knew that he actually understood it and meant it"* (Angie, emphasis in the original, MAXQDA 33).

This communication of concern could be exhibited nonverbally through physical support in managing the symptoms of SLE. For example, Nicole indicates:

I have seen him take time off work to stay home and be with me. When I was at my worst with the fever, and it was so cold and I couldn't get warm. He would start a fire and a kerosene heater and basically bake me all day long. By the time he got home everything was dying down and he would crank it out again. He was very supportive that way and has been all along (Nicole, MAXQDA 28).

Concern was also communicated in the provision of emotional support, as demonstrated in this tender exchange between Sarah and her spouse *"He didn't say a lot. He just held*

me and let me cry it out. And he said, it's gonna be okay. But just to validate you know what I was feeling was really critical” (Sarah, MAXQDA 56).

In addition to open communication about the disease and the consistent communication of concern, the third characteristic of this SLE family myth was that family members either embraced the attempts of the patient to educate them about the disease or actively initiated their own education about the disease.

I can think when [her husband] and I first started dating I guess this would be the example I would use, you know you're always hesitant, I've not been in the dating world, I'd been married for 28-29 years this was casual, but for some reason I just said, you know I have lupus and he started asking questions and so I said there's something I can give you to read and it was from NIH and it was for patients and families and I thought that will be the end of it. He won't read it or anything, but at least I told him. But he came back and he had read it. And asked questions and he does that now. He'll pick up lupus magazine and read an article and ask questions (Elise, MAXQDA 54).

Harmonious SLE family myths were not without their challenges, but families triumphed over the challenges of the illness. For example, Angie describes the moment when her spouse began to accept the chronicity of her disease as critical to her illness experience. She explained to him that, after years of him expecting her to maintain the same responsibilities as she had before getting sick, her illness required a change in his expectations of her. She needed him to accept that she was not going to get better and they had to adjust their life to match that reality:

I laid out for him one day and said if you can't get over being mad at me and the fact that you have to now take care of me, then you have to go. Because I don't have the energy to deal with lupus and your being mad at me too. Join a support group if you have to, but if you're not going to be what I need you can just go. And he's still here! (Angie, MAXQDA 27).

In summary, the harmonious SLE family myth can be summarized in terms of the perception that SLE is a *family* disease, not an individual disease. Shannon describes this over-arching theme clearly when she states about her husband “*So he's you know, he's learned a lot and it's kind of like we have lupus as opposed to I have lupus*” (Shannon) This sense of togetherness and shared ownership of the disease was communicated through open family communication about SLE, a clear communication of concern, and a sense that the family wanted to become educated about SLE.

Abandoned SLE Family Myth

Seven of the participants (25%) in this study demonstrated an abandoned SLE family myth. In this family myth, women feel alone in their illness journey and are often unable to discuss their illness experience with their family members. Six of the seven participants in this SLE family myth had ambivalent chaos narrative plot lines, and one of them had a contaminated restitution. The themes characterizing this family myth are an overall feeling of loneliness, the perception that others actively avoid talking about SLE, and the participant feels silenced and thus inhibited from initiating conversations about SLE. Further, six of the seven participants reported both avoidant and disconfirming communication, though one participant who was facing a life threatening crisis at the time of the interview reported avoidant and confirming family communication. Joan

explains how her family was not open to conversations about SLE but she still felt a sense of concern that confirmed her struggle with the disease:

And I pretty much accepted that no one wants to hear about woah is me, it gets old. But soon they were off to college and you know so they didn't have to deal with if I had flared or not feeling well that kind of thing as much. But they're very worried about it because each time I have a flare it seems to be worse and last longer (Joan, MAXQDA 22).

Here, Joan talks about how she both feels silenced in her family because she perceives that her family does not want to hear her complain. Later in the interview, she contradicted this statement indicating that her family does want to talk with her, but she doesn't want to discuss SLE because she does not want to be emotional. This expressed discrepancy in perception belies a chaotic narrative plot line. Further at the time of this interview, she was facing a life-threatening flare and, though she expressed that she felt silenced in talking about SLE, she also expressed her perception that her family members worry about her and that this was confirming for her:

Oh. I'm gonna have to discuss it tonight (laugh). I'm gonna let them all know that I'm going in for surgery and I'm sure that it will be emotional. And I'm sure they'll be flying home. That's just what I know they'll want to do (Joan, MAXQDA 24).

These participants reported feeling lonely in their illness experience, reporting that others did not care or could not handle their disease. Celeste explains “*I don't know it's like they don't really care, it seems like. It's kind of a lonely feeling actually*” (Celeste, MAXQDA 18). She goes onto exemplify how this loneliness was accompanied

by the overwhelming feeling that others did not wish to talk about the illness, even when the symptoms were clearly visible:

It just doesn't even come up. And even if I'm at my daughter's house or something and I have the rash or I have a bad headache, they just say "oh that's too bad" you know and then they change the subject (Celeste, MAXQDA 18).

Participants positioned in the abandoned SLE family myth overwhelmingly report that they are actively prevented from talking about their lupus. Family members tended to discourage honest explanations of lupus symptoms “Well I can talk to my brother and my sister, they just don't want to hear about it. It's like, tell me everything is wonderful” (laugh) (Amy, MAXQDA 10).

Though many of the women in this study reported tension between the implications of their illness and their gendered social positioning as caretaker, the women in this narrative tended to cite this as a reason to not talk about their illness struggle with family members. For example, Stephanie explains the pressure she felt to avoid burdening her family that resulted in silencing her struggle, ultimately limiting the much needed social support she received from her family.

That's a part of the problem I'm also having is the pressure that I'm feeling the pressure of still trying to be there for everybody as well as to not burden everybody. So I was still trying to compartmentalize it all. I was still trying to not let my illness that impacts others. And not be burdensome for the entire family. I was still trying to do that. I was taking care of all my expenses. My dad was really helping still. He would come by every day, every day. So that has been a constant.

But in terms of expenses and stuff like that I was trying to manage on my own and not let it be a burden to anyone else but myself (Stephanie, MAXQDA 26).

The abandoned SLE family myth, then, is characterized by a feeling of loneliness, the sense that family members did not want to talk about the illness, and a feeling that they were not free to discuss their disease in their families (i.e. they were silenced in their families). Family communication was avoidant and disconfirming, and the women in this SLE family myth were predominantly making sense of their SLE primarily from an ambivalent chaos narrative plot line.

Battle SLE Family Myth

Six of the participants (21%) in this study described a battle family myth. This family SLE myth is primarily characterized by a discrepancy between family members in orienting toward the illness and consists of avoidant and disconfirming family communication. The SLE narrative plot lines in this family myth tended to be contaminated life-as-normal, though there was one contaminated restitution and one ambivalent life-as-normal. A tension between family members in orienting toward SLE (i.e. adopting a restitution narrative plot line versus a quest narrative plot line) often resulted in conflict and the absence of necessary social support in the illness context. Amber highlights how her life-as-normal narrative plot line and her son's restitution narrative plot line resulted in relational tension:

I just tell them this is what it is and I'll have to get through it and you'll just have to understand that I'm totally not functional right now. They've seen a change in me, I mean they know it. Cognitively everything. You know, my son made the comment, "You can't remember what you had for breakfast" and I said "You

know you're right but I don't need to remember that". They realize it, but they still don't quite get it and I don't know how to make them get it. I really don't (Amber, MAXQDA 29).

Oftentimes participants described the perception that family members expected them to engage in restorative behaviors that were beyond their capabilities. This often led to self-doubt and strained relationships. Amber explains how this tension plays out as well:

Well one of my sons just said "you just need to get up". He made a food plan for me and an exercise for me. "You just need to push through this Mom". I'm a single mom and I raised my kids by myself so they've seen strength. So they said "You can do this, you can push through this I know you can I've seen you". And I'm like, I can't even get up to go to the bathroom. I'm not doing any exercises. And it felt very difficult for them to accept. You know one day my son said finally, "Would you just try. I worked out these stretches for you" and I said "I'll try" and when he saw how difficult it was for me to do the stretches, he was like "Wow" (Amber, MAXQDA 29).

Women operating within the battle family myth often reported the sense that their family was once open to talking about the disease, they've mostly grown tired of it.

Melissa explains:

I think though after a year and a half, I think everyone kind of gets a little tired of you of me being not up to you know part of it is age I think too. I think yeah, they get a little bit tired of hearing I don't feel good, or its tough for me, or doing some of the things I used to do which was great hiking out in the sun and that and I

know I don't do to the extent because I know I'll pay for it either with a couple of days of exhaustion or another flare up of another episode. So, it's kind of a drag. I think, and you know they KNOW, but again I think the novelty of it has worn off and this is the way life is and it's kind of a drag (Melissa, MAXQDA 22)

This family myth was also characterized by a feeling of embattlement with an expressed need for women to defend themselves and their illness-related needs and decisions. Allison explains:

So, he made a remark about being the only one, having to wanting to review who I gave money to because after all I wasn't working. And it just pissed me off. So it had more to do with the consequences of dealing with the disability than it did about specifically about lupus or the physician's appointment. He does think, we've had conversations about the amount of drug that I still take. And he just kind of made it clear that he would not do that (Allison, MAXQDA 28).

Additionally, women struggling with SLE often find themselves in a position to have to decline family invitations. Melissa explains how this becomes a point of struggle within this SLE family myth:

I think the times when I've had to defend myself when I've had to explain that, no it's not that I don't like you and it's not that I don't want to have fun playing cards with the family, it's just that I don't have the energy (Melissa, MAXQDA 34).

In summary, the battle SLE family myth is characterized by family tension. Family communication is avoidant and disconfirming. Women describing the battle family myth

express a feeling of embattlement and struggle within their families regarding their SLE, and tended to have contaminated life-as-normal narrative plot lines.

Summary of SLE Family Myths

In answer to Research Question 3, this cross-case data matrix analysis yielded three distinct SLE family myths (harmonious, abandoned, and battle) that emerged from different combinations of SLE narrative plot lines and distinct family communication behaviors. This findings of these three distinct SLE family myths contributes both to the literature on family communication and illness narratives and to the literature on mixed methods research. First, these SLE family myths support the value of using cross-case data matrix analysis in moving between qualitative and quantitative data sets in an exploratory sequential mixed methods research design. One of the primary challenges to validity in this type of research design is justifying the way the qualitative data is merged into the quantitative design (Creswell, 2015). In transforming qualitative data into a variable, you run the risk of losing the richness of the qualitative data and for this reason, this type of analysis is often criticized by qualitative researchers (Miles et al, 2014). However, Miles, Huberman, and Saldana (2014) explain that the cross-case data matrix analysis is used in conjunction with a thematic analysis in order to both honor the idiosyncratic nature of the qualitative thematic analysis and to build from those themes to enhance the transferability of the findings. In this analysis, the themes that emerged in the qualitative thematic analysis were the foundation for the cross-case data matrix analysis and the findings of this second analysis were then used to develop a variable specific to this population that can be used to facilitate more population specific research. This will help to address the fact that this population is under-studied (Wallace, 2008).

Second, this finding contributes to the literature on narrative sense-making in illness in that it both provides support for the centrality of family communication processes in the narrative sense-making in illness and extends Frank's (1995, 2013) cognitive conceptualization of illness narrative types to account for the communicative nature of sense-making (Koenig Kellas, 2005). Thus, these findings provide the foundation for exploring the role of communication in which of the illness narrative types are more or less prevalent in the sense-making of individuals with SLE (Frank, 1995, 2013). This both acknowledges individual and family agency in shaping the experience of chronic illness, an experience that is characterized by a loss of control (Charmaz, 2000), and provides a strong foundation for the development of family interventions aimed at promoting communication that will encourage the adoption of healthier, more productive illness narrative plot lines.

These family myths were reflections of the individual's perception of their family in light of SLE (e.g., supportive or unsupportive). Given the importance of an individual's perception of family social support to the management of chronic illness (Rosland et al, 2012) and the identification of SLE family myths as a unique variable specific to the experience of SLE, the need to better understand SLE family myths is evident. Thus, consistent with CNSM, this variable was positioned in Study 2 as an independent variable to test whether SLE family myths correlate with physical and mental health, family satisfaction, and self-management behavior.

CHAPTER 5

DISCUSSION STUDY 1

The results reported in this study point to several important observations about CNSM in the experience of SLE. First, as expected, Frank's (2013) typology of personal illness narratives combined with McAdams' (1993) concept of narrative tone was a useful conceptualization of illness narrative types in the context of SLE. Further, it was clear that SLE narrative plot lines do, in fact, animate women's perceptions of their illness experience, providing support for the research objective posed for Study 2 aimed at identifying the illness narrative types of women with SLE in order to correlate them with measures of physical, mental, and relational health and well-being (2013).

Second, in line with Koenig Kellas and Kranstuber Horstman's (2015) assertion that families communicate to make sense of difficulty, it was clear that family communication was intertwined in meaningful ways with the SLE narrative plot line that was most prevalent in these women's descriptions of their illness experience. This finding provides support for undertaking the second study in this mixed methods research project. Specifically, it suggests that family communication processes and SLE narrative plotlines work in tandem (i.e. SLE family myths) to shape sense-making in SLE. Further, the presence of distinct SLE narrative plot lines suggests a need to explore whether these narrative plot lines have implications for health and well-being.

Third, consistent with existing literature on family communication in chronic illness, a tension between openness and avoidance emerged as an important communicative paradox in managing the experience of SLE in families (i.e. Caughlin et al., 2011). In their review of the literature on family communication behavior in chronic

illness, Rosland and colleagues (2011) explain that disease specific social support is more important than general social support in improving health outcomes (e.g., Gallant, 2003). However, the participants in this study who were managing SLE in abandoned and embattled families often engaged in and experienced disease-specific avoidance, highlighting the difficulty associated with this relational protection strategy in the context of SLE.

Fourth, it was also clear in this study that *family* was defined by these participants as including both the family of origin and the nuclear family, with communication in one differing sometimes dramatically from communication in the other. Despite these distinctions, these participants described their *overall* perception of their family in relation to their illness. Thus, Study 2 asks participants to self-define family when responding to survey questions in order to get a clear picture of participant perception of their family communication overall.

Fifth, though Mendelson (2006) conceptualizes the time pre-diagnosis as a period of identity in abeyance, it is clear from these present data that the self is constantly emerging in and through experience. Consistent with Charmaz' (1995) assertion that identity (re)construction in illness begins with the onset of symptoms, these women narratively made sense of the experience of illness from the first indication that something was amiss. Thus, as highlighted by CNSM (Koenig Kellas & Kranstuber Horstman, 2015), though diagnosis was important to achieving a coherent narrative, sense-making and identity construction as a *process* occur throughout the experience of illness, beginning with the initial observation that something is wrong (Charmaz, 1995). Thus, the results of this study support CNSM as a useful and important framework for

understanding family sense-making in the context of illness, specifically, SLE. As the guiding theoretical framework, CNSM provided the space to identify patterns across individual accounts of the experience of SLE to determine if/how particular illness narrative types emerged, thus providing a way to thematize a traditionally idiosyncratic experience (Frank, 2013).

Further, the themes discovered in Study 1 will be used as a central part of Study 2 to see if these more specific conceptualizations of narrative sense-making in SLE are related to measures of health and well-being. In other words, the quantitative strand of this project (in Study 2) will determine whether the SLE narrative plot lines, family communication behaviors, and the SLE family myths identified in Study 1 predict physical and mental well-being, family satisfaction, and self-management behavior. Guided by Frank's (2013) and McAdams' (1993) thorough descriptions of illness types and narrative tone, these themes will be used in conjunction with family communication behaviors to identify particular SLE family myths that can be correlated with measures of health and well-being. Thus, I argue that CNSM provides the space to move in a theoretically driven way from a social constructivist exploration of experience that enabled an enhanced, nuanced understanding of women with SLE (Study 1) to a post positivist orientation in Study 2. This move will enable a quantitative exploration to determine if this more nuanced representation is indeed representative of the larger population of women with SLE. This will provide the foundation for interventions for families living in the context of SLE that are informed by and tailored to the idiosyncratic nature of SLE. Further, it will enable an exploration of what types of family communication behaviors and illness narrative plot lines encourage an emphasis on more

healthy and productive SLE family myths as women make sense of their SLE experience within their families.

CHAPTER 6

STUDY 2 RATIONALE

In Study 1, SLE narratives were analyzed in terms of illness narrative type, narrative affective tone, and family communication. Results indicate six narrative plotlines and four primary family communication behaviors most prevalent in the experience of the SLE participants interviewed. Thus, Study 1 showed that women with SLE make sense of their illness in their families guided by a distinct SLE narrative plot line and that their family communication is fundamentally characterized by avoidance, openness, confirmation, and disconfirmation. Further, the results of the cross case data matrix analysis demonstrated that the narrative plot lines and family communication behaviors interact to shape a distinct SLE family myth that may have important implications for these women's health and well-being as they manage their illness. Thus, these findings suggest that family communication behaviors and SLE narrative plot lines together shape narrative sense-making in unique and potentially important ways for women with SLE.

In order to better understand the experiences of women with SLE and improve their overall health and well-being, it is essential that we study it in ways that both honor the idiosyncratic nature of this condition (Mendleson, 2006; Wallace, 2008) and uncover communicative patterns (Miller, 2000) that can inform interventions aimed at enhancing health and well-being for those managing SLE. Thus, true to the purpose of an exploratory sequential mixed methods research design (Creswell, 2015), the first purpose of Study 2 is to engage in integration, by creating and testing the viability of the two population specific variables that emerged in Study 1 (i.e. SLE narrative plotlines and

SLE family myths). These two variables have the potential to allow for research that reflects the experiences and meets the needs of this population as they struggle to manage this disease in their family relationships. Thus, the first purpose of Study 2 is to integrate the qualitative findings with quantitative methods to create two variables through which we can study SLE as a unique illness experience, providing more nuance to our research of this population.

Second, in order to undertake research that has the potential to enhance the health and well-being of this population, we have to determine if/how specific approaches to narrative sense-making and family communication behaviors relate to health and well-being in SLE. Thus, Study 2 was designed to determine if narrative sense-making (the SLE narrative plotlines that emerged in Study 1) and family communication behaviors (open/avoidant, confirming/disconfirming) were related to physical and mental health, family satisfaction, and self-management behavior. Given the centrality of communication to narrative sense-making (Koenig Kellas, 2005) and the importance of honoring the unique features within the SLE experience (Wallace, 2008), Study 2 is designed to examine these relationships using the variables that emerged in Study 1. Specifically, Study 2 will first examine if/how SLE narrative plotlines and family communication behaviors relate to health and well-being in SLE as independent constructs. Second, it will examine how the more global operationalization of SLE family myths relate to health and well-being in SLE. Examining all of the variables (plotlines, family communication behaviors, and myths) will provide a nuanced window into the predictors of well-being for SLE women in ways that will hopefully inform future intervention efforts.

The process of narrative sense-making has been linked to health and well-being (e.g., interactional sense-making, Koenig Kellas et al., 2013) and re-storying difficult or potentially negative experiences is beneficial to health and well-being (e.g., health legacies, Manoogian, Harter, & Denham, 2010). We also know that family communication is central to well-being in illness (Pecchioni et al, 2015) and that women with SLE often report that their disease strains their family relationships (Roper Public Affairs, 2011). Despite this, the significance of narrative sense-making for well-being, and the centrality of family communication to narrative sense-making, we do not yet know what implications for health and well-being are associated with the interdependent nature of family communication and narrative sense-making in SLE as represented by the analysis of SLE narrative plotlines, family communication behaviors, and SLE family myths (a combination of plotlines and communication behaviors). Examining this will further establish narrative sense-making and family communication as central to well-being in SLE and it will provide a foundation for positioning communication as central to Frank's (1995, 2013) cognitive conceptualization of illness narratives. This will enable a more nuanced understanding of how family communication and specific illness narrative plotlines interact in ways that have implications for health and well-being.

The examination of these links in Study 2 was grounded in CNSM which looks at the communicative nature of narratives (Koenig Kellas, 2005) using a post-positivist framework that enables the identification and correlation of patterns in narratives with measures of health and well-being (Koenig Kellas & Kranstuber Horstman, 2015). Thus, working from the thematic patterns identified in Study 1, and true to the intent of this exploratory sequential mixed methods design (Creswell, 2015), the purpose of Study 2 is

to build from the findings in Study 1 to gain a more comprehensive understanding of women's narrative sense-making in SLE (See Figure 1).

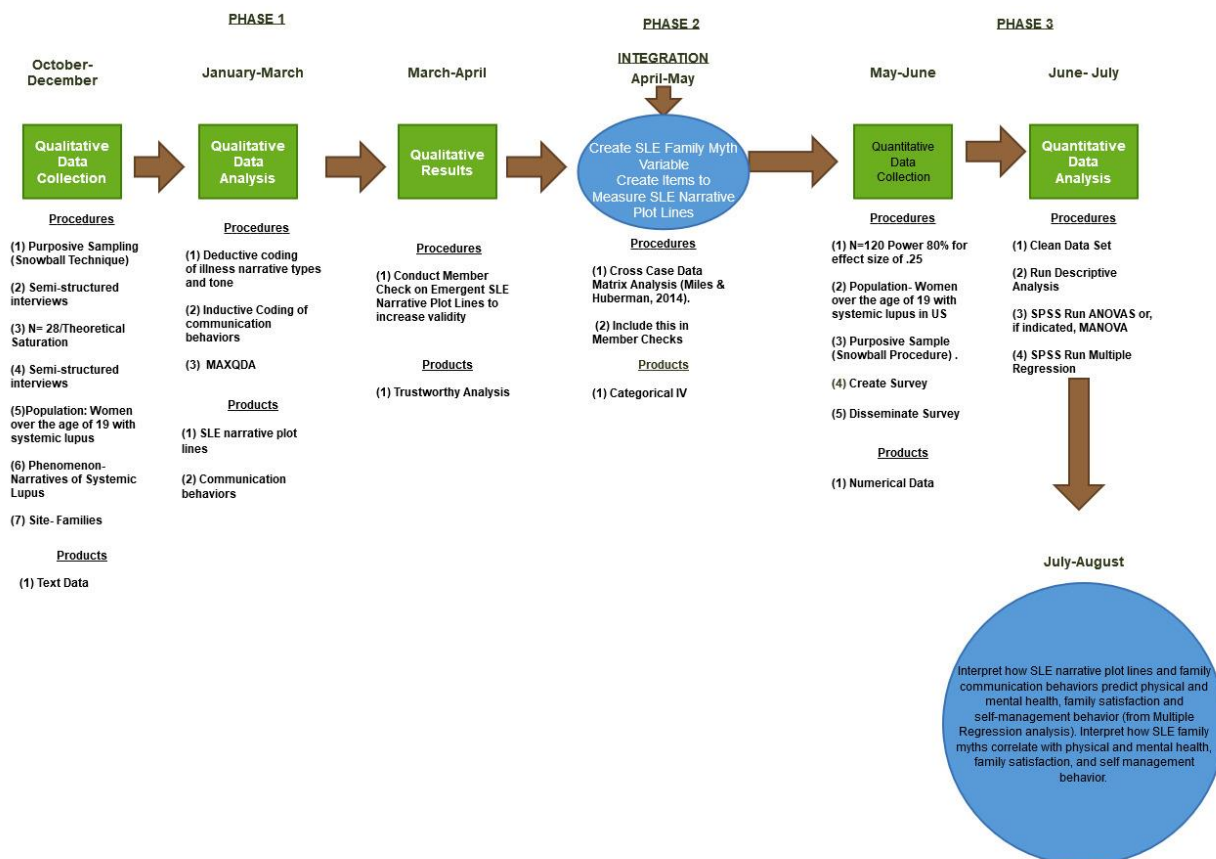


Figure 1. An Exploratory Sequential Mixed Methods Design of Women's Narrative Sense-Making and Family Communication in SLE

Linking Narrative Plotlines and Family Communication with Psychosocial Well-Being and Family Health

Narratives affect and reflect coping with difficulty and illness (Koenig Kellas & Kranstuber Horstman, 2015). This has been demonstrated qualitatively in Frank's (1995, 2013) development of an illness narrative typology as well as in Wittenberg-Lyles, Goldsmith, Sanchez, & Ragan's (2011) typology of family narratives in the context of palliative care that delineate and describe distinct family experiences with palliative care. Sunwolf and colleagues (2005) explain the healing effects of story sharing for the story teller and the story listener while Bistocco and Thompson (2005) and Koenig Kellas and Keeley (2005) demonstrate the importance of narrative for facilitating coping through bereavement.

Other research examines these links quantitatively, thereby reinforcing the importance of narrative sense-making for physical and mental health and well-being. For example, Koenig Kellas et al. (2010) explore the connection between interactional sense-making and well-being as couples jointly tell stories of stress, finding that higher levels of interactional sense-making behavior were linked to lower levels of husbands' reported stress. In addition to being linked to mental well-being, stress is clearly linked to physiological well-being in that it is linked to general susceptibility to illness as well as being connected with negative outcomes in specific illness contexts (Lazarus & Folkman, 1984). Further, McAdams, Reynolds, Lewis, Pattern, and Bowman (2001) found that redemptive narratives were positively linked and contaminated narratives were negatively linked to mental health and well-being.

Despite this, little research has examined these links quantitatively and none in the context of SLE. This is problematic because SLE is a prevalent yet misunderstood and often mis-managed disease with serious physical and mental implications (Aberer, 2010; Wallace, 2008). Women with SLE report that SLE negatively affects their family relationships (Roper Survey, 2011). This is concerning given growing evidence that social behaviors impact health outcomes (Shapiro, 2002) and that the social support and coping resources provided in family communication (Pecchioni et al., 2015) are clearly linked to improved outcomes in chronic illness (Rosland et al., 2011). In fact, one fundamental way that families provide coping resources is through storytelling (Koenig Kellas, 2010). Narrating illness and difficulty can benefit sense-making, individual, and relational health (Frattaroli, 2006; Koenig Kellas & Kranstuber Horstman, 2015), and families are a central site for this type of sense-making (Pecchioni & Keeley, 2011). By empirically establishing links between narrative sense-making about SLE in the family with measures of health and well-being, we can begin to conceptualize the types of narrative sense-making that affects and reflects the psychosocial health of women with SLE and develop interventions aimed at promoting family communication and sense-making that are relevant and useful for women, families, and medical providers managing SLE. In order to test these links, I will examine how the SLE narrative plotlines and family communication behaviors relate to physical and mental health as illustrated in the following research questions:

RQ1: How do SLE narrative plot lines and family communication behaviors predict physical health?

RQ2: How do SLE narrative plot lines and family communication behaviors predict mental health?

In addition to individual health, research also has established important links between narratives and family functioning. For example, Koenig Kellas (2005) found links between themes of family stories and family satisfaction, functioning and overall well-being, such that families who told stories of accomplishment and appreciation (i.e., redemptive stories) were happier in their families than families who told stories of stress (i.e., contaminated stories). Vangelisti, Crumley, and Baker (1999) found that the themes that characterized the stories that people tell about their own families are associated with family satisfaction such that families that were more satisfied told stories reflecting care, togetherness, reconstruction, and humor and families that were less satisfied told stories that reflected disregard, hostility, chaos, and that revealed a discrepancy in values. Further, the results of Study 1 support the idea that certain SLE narrative plotlines are animated by a more functional (or at least more satisfying) family environment.

Illness itself alters social relationships (Beach, 2002) and changes the way families interact with one another (Miller-Day, 2011), sometimes creating barriers to family communication (Caughlin et al., 2011) in a time when many family members experience an increased need for information and emotional closeness (Hay et al., 2009). Given the importance of family in making sense of difficulty like illness (Pecchioni & Keeley, 2011), providing the social support and coping resources so important to facilitating positive health outcomes in illness (Rosland et al., 2011), and the impact of narrative on family functioning (Koenig Kellas, 2005), it is vital that we understand how

narrative sense-making in illness and family communication impact family satisfaction in SLE. Study 2 examines this by asking:

RQ3: How do SLE narrative plot lines and family communication behaviors predict family satisfaction?

Finally, research has not yet investigated links between narrative sense-making and self-management behavior. As chronic illness continues to increase in prevalence (Shapiro, 2002), there is a shift in care from within to outside the clinical setting (Telford, Kralik, & Koch, 2006) characterized by patients self-managing their chronic illnesses every day. In fact, the question is not *are* they managing their illnesses, but *how well* are they managing their chronic illnesses as they make daily decisions that impact the course and severity of their disease process (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Self-management behavior is critical to the success of chronic illness management (Telford et al., 2006). Despite the clear importance of self-management behavior in managing chronic illness, as well as evidence that general family social support impacts self-management behavior, and, in fact, affects specific self-management behaviors differently than others, there has been surprisingly little research positioning self-management behavior as an outcome of family behaviors (Rosland et al, 2012).

Self-management behavior is therefore necessary for the proper management of chronic illness, particularly in an illness like SLE. In addition to a regular medication and treatment regimen (e.g., anti-malarials, anti-inflammatories, steroids, and immunosuppressive therapies), women diagnosed with SLE are also required to change their lifestyles, sometimes dramatically, to manage their disease. For example, proper management of SLE requires avoiding sun exposure, getting adequate rest, eating a

proper diet, and maintaining a regular exercise schedule (Aberer, 2010; Wallace 2008). However, this type of self-management behavior is often inhibited in chronic illness as patients seek to minimize the visibility of these behaviors to avoid the stigma associated with chronic illness (Gallant, 2003). For example, an SLE patient may opt to join their family for a day at the ball park or on the beach to minimize the visibility and impact of their disease on their relationships at the expense of disease management, causing a flare up of SLE symptoms.

Thus, self-management behavior involves managing both the illness and the lives of those affected by the illness. It requires work, both for the patients and the family members that live with them (Corbin & Strauss, 1985). Additionally, family communication, particularly communication that provides disease-specific support, is associated with better self-management in chronic illness (Rosland et al., 2012). Thus, given this, the fact that narrative sense-making about illness inherently involves the family (Kleinmann, 1988) and that self-management behavior is central to the successful management of SLE, it is crucial that this study's focus on implications of narrative sense-making and family communication for health and well-being include an exploration of self-management behavior. Thus, the final research questions posed in this study is:

RQ4: How do SLE narrative plot lines and family communication behaviors predict self-management behavior in SLE?

In addition to predicting physical and mental health, family satisfaction, and self-management behavior, the cross case data matrix analysis findings indicate that these family communication behaviors and SLE narrative plotlines may be parsimoniously

combined into one of three SLE family myths that reflect the individual's perception of their family identity in relation to SLE. Koenig Kellas (2005) argues that narratives are inherently communicative, an idea that is reinforced in her assertion with Kranstuber Horstman (2015) of CNSM as a conceptual model organizing research focused on the communicative nature of narrative sense-making. As a variable comprised of a combination of narrative plotlines and family communication behaviors, these SLE family myths represent an important opportunity to advance research that both centralizes communication in narrative sense-making (Koenig Kellas & Kranstuber Horstman, 2015) and embraces the significance of family in narrative sense-making processes (Pecchioni & Keeley, 2011). Given the centrality of family in providing social support in illness (Pecchioni, Overton, & Thompson, 2015), the significance of the perception of social support in managing chronic illness (Rosland et al., 2012), and the clear links between narrative sense-making and health and well-being (e.g., Koenig Kellas et al., 2010), Study 2 explores whether these three family myths are related to physical and mental health, family satisfaction, and self-management behavior.

In exploring the whether a combination of narrative sense-making and family communication behaviors predicts health and well-being in SLE, this study not only embraces Koenig Kellas' (2005) call for studying narratives as communicative, it responds to Miller-Day's (2011) assertion that health and family communication should be studied as interdependent processes. It is essential that we explore the interplay between family communication behaviors and SLE narrative plot lines theoretically and pragmatically. First, it is important from a theoretical standpoint as it will help to explain how the interaction of communication and narrative sense-making affects health and

well-being in SLE, thus extending Frank's (1995, 2013) and McAdams' (1993) cognitive conceptualization of narrative to a communicative conceptualization and further exploring the communicated nature of narratives (Koenig Kellas, 2005). Second, the creation of a variable comprised of specific SLE narrative plotlines and family communication behaviors not only provides insight into sense-making about SLE but also a means by which women with SLE and their families can claim agency in that process through communicative choices in the family. In other words, a variable that reflects the communicative nature inherent in sense-making about illness also embraces the empowering nature of narrative sense-making in an illness context. Thus, I will examine how the synthesis of narrative plotlines and family communication, as operationalized by SLE family myths, relate to measures of health and well-being in SLE. The final research question asks whether these gestalt family myths can explain differences in each of the dependent variables:

RQ5: How do SLE family myths help to explain differences in (a) physical health (b) mental health (c) family satisfaction (d) self-management behavior in SLE?

CHAPTER SEVEN

METHODS STUDY 2

Recruitment

After securing IRB approval, I recruited participants in a similar way as Study 1, though on a larger scale. Participants were required to meet the same inclusion criteria as were specified in Study 1. I engaged in purposive sampling, disseminating a recruitment script that included a description of the study, requirements for participation, and a link to the survey. I also engaged in snowball sampling (Noy, 2006) given the importance of this approach in accessing hard to reach populations like women with SLE. Thus, my recruitment script included a request to forward the call for participation on to others. In addition to sending my call for participation out to my informal networks, I sought and was granted approval to post an approved call for participation in several online SLE, autoimmune diseases, and chronic illness online communities, to include Facebook groups, Google Plus groups, and LinkedIn groups. Additionally, I requested that the call for participation be posted on community and national organization websites, including the Lupus Foundation of America, Lupus in Lincoln, and The Lupus Foundation of Florida. I also received permission to post my call for participation in online forums specific to managing lupus, such as the Healing Well with Lupus online forum. Finally, I disseminated my call for participation to rheumatologists and medical centers requesting that they share my call for participation to their patients.

Participants

Of the 186 participants that began the survey, 137 finished it, and a majority of the items were completed by 112 participants. These individuals were females that

ranged in age from 21 to 71 ($M=44.00$, $SD=11.4$). Of the participants who reported ethnicity, 117 (69%) were Caucasian, 20 (11.9%) were African American, 10 (6%) were Hispanic, 9 (5.4%) were Asian, 4 (2.4%) were Native American, and 8 (4.8%) reported Other. 96 (52%) of the participants were married, 3 (2%) were widowed, 28 (15%) were divorced, 5 (2.7%) reported being separated, and 35 (18.8%) reported that they were dating. One (.5%) participant reported a grade school education, 39 (21%) reported a high school education, 56 (30.1%) held a bachelor's degree, 31 (16.7%) held a master's degree and 6 (3.2%) held a doctorate, and 34 (18.3%) reported Other, indicating trade school and other specialized training (e.g., Cosmetology). 90 (48.4%) of the participants reported that they were currently working and 78 (41.9%) reported that they were not currently working, and 18 (9.7%) did not answer this question. 94 (50.5%) reported that their organs had been affected by SLE while 65 (34.9%) reported no organ involvement¹, and 27 (14.5%) did not answer this question. 44 (23.7%) reported that their disease was visible to others while 113 (60.8%) reported that their SLE was not visible to others, and 29 (15.6%) did not respond to this question. 22 (11.8%) of the participants reported having completed other studies about SLE in the last 12 months whereas 135 (72.6%) reported that this was the only study related to SLE that they had participated in within the last 12 months, and 29 (15.6%) did not respond. Finally, participants varied in their time since diagnosis, with the number of months since diagnosis ranging from 13 to 518 ($M=143.66$, $SD=105.01$).

Procedures

¹ This question refers to whether or not SLE has attacked any organs in the body. It was included because organ involvement in SLE is indicative of more serious disease activity and could shed some light on the experiences of the participants in this study (Wallace, 2008).

The data for this study were derived from participant responses to an online survey. The survey was constructed using measures of the variables of interest. Whenever possible, the measures selected have been demonstrated to be reliable and valid, though some new measures were created to meet the needs of this study (See Appendix B). The survey was administered through Qualtrics, a secure online survey software system. When participants received the call for participation during the recruitment phase, they were able to click on the survey link and be directed to the informed consent for the study. They were required to indicate that they had read, agreed that they qualify, and understand the study and their rights as a participant by clicking a box indicating their agreement. They were not able to access any portion of the survey until they had provided their informed consent in this manner. My contact information was included on the informed consent form as well as on the recruitment script so that they were able to contact me with any questions or concerns they may have had regarding the study.

Integration and Measures of Independent Variables

A crucial step in mixed methods research is the integration of qualitative and quantitative strands of research. Despite the fact that integration of qualitative and quantitative data is critical in a sound mixed methods project (Creswell & Plano Clark, 2011), the extent to which mixed methods research actually engages in explicit integration of qualitative and quantitative data remains limited (Fetters, Curry, & Creswell, 2013). This study explicitly integrates the qualitative and quantitative data by creating two new variables: a new categorical population specific variable that emerged in the cross case data matrix analysis from Study 1 (SLE family myths) and a continuous measure of narrative plotlines. Thus, I engaged a two-step integration process in order to

detail creation of each new variable and thus enhance the validity of this exploratory sequential mixed methods research project (Creswell, 2015).

SLE Narrative Plotlines Variable

Because narrative sense-making can be a complex process and one that changes over the course of the illness journey (Frank, 1995, 2013) and in order to assess the nuanced ways in which narrative plotlines combine with family communication behaviors to predict well-being and self-management, I responded by creating a continuous measure of narrative plotlines. Items for each of the six narrative plotlines were created based on participant discourse that emerged in Study 1.

Measure of SLE narrative plot lines. The SLE narrative plot lines were measured using a 27-item, 5 point Likert scale created for this study and informed by participant responses from Study 1 (means, standard deviations, and alphas for all dependent and independent variables are listed in Table 5). Each of the SLE narrative plotlines were represented by either four or five items. Participants were asked to rate the degree to which they agreed with statements (e.g., I have accepted SLE as a normal part of my life) on a five-point scale (1=Strongly Disagree, 5=Strongly Agree). Items were created to reflect the experience articulated by the interviewees. In order to increase the validity of the items and remain true to the intent to accurately reflect participant experience in Study 2, items were created using participant language wherever possible (Creswell & Plano Clark, 2011). The integration of findings from Study 1 into scale items to measure this variable for Study 2 is visually depicted in a joint display (see Table 2).

Table 2 Joint Display of SLE Narrative Plot Lines Item Creation

Sub-themes	Representative quotes	Items-rated on a 5 point Likert Scale
SLE Narrative Plotline 1: Ambivalent Life-as-Normal (10 participants)		
Sub-theme 1: Desire to preserve normalcy for self.	But, if I want to clean my house, and scrub my toilet and do all the things that I'm SUPPOSED to be able to do at 44 years old, I'm okay with that. I'm okay with having a busy day and not feeling great at night. Because I want as much of a normal life as possible (Kara, MAXQDA 46).	1. I have accepted SLE is a normal part of my life 2. When I have symptoms, I do what I can to keep things normal for myself.
Sub-Theme 2: Desire to preserve normalcy for others	There was no reason to get him upset, I just wanted his life to be as normal as possible (Carol, MAXQDA 24). Well I don't want my daughter to worry, so I pull back a little bit for her. She's just moved to Australia, so she went to college there so she just moved back and married her long term sweetheart and they're trying to get pregnant and I don't think the stress will be good for her, so now I'm holding back. So I don't stress her, so I'm holding back right or wrong (Tara, MAXQDA 26).	3. When I have symptoms, I do what I can to keep things normal for my family.
Sub-Theme 3: Matter of fact acceptance of unpredictability of SLE.	I mean I just never knew what it was going to throw my way. And over time I thought, well, I'm resilient I'll just have to role with whatever comes (Nicole, MAXQDA 10).	4. I've accepted that I will just have to roll with what SLE throws my way.

Sub-Theme 4: Acceptance that SLE is not going away	Lupus is part of my life, it was, you know, a disorder that I had that I was dealing with and that I was always going to deal with, so it was going to be part of my life and is for the rest of my life (Jodi, MAXQDA 46).	5. I've accepted that SLE is here to stay.
SLE Narrative Plotline 2: Ambivalent Chaos (6 participants)		
Sub-Theme 1: Over-Determination of Difficulty	And my doctor said that this was gonna go in the medical journal because it was a new side effect. Yeah. That was not good. So you know with lupus you have all kinds of crazy stuff. And with all that crazy stuff comes mounting doctor's bills which are never ending if your lupus doesn't go into remission. And so I'll tell you what to try to stay positive and you know, it's hard, it's just really hard to stay positive through all that (Kaitlin, MAXQDA 4).	1. Every day is a struggle with SLE. 2. When I have symptoms it feels like they will go on forever. 3. I have difficulty with all aspects of my life because of SLE.
Sub-Theme 2 Emphasis on uncertainty	Which is basically what lupus does, your body attacks whatever it wants. Whatever organ it wants. And or, they said it could be caused from long term steroid use. Well, you know, what are you gonna do, because I need the steroids for my lupus. Right now I'm just waiting and wondering (Kaitlin, MAXQDA 4).	4. I feel like I'm always waiting and wondering what's going to happen next.
SLE Narrative Plot Line 3: Ambivalent Quest (4 participants)		
Sub-Theme 1: Use SLE experience to help others with SLE	Between the PCP fellow who wasn't taking me seriously at all. I think I had been in this car accident and I think he thought I was trying to build a case for the insurance company because I kept saying I feel sick, I ache all over, tired, and odd aches and pains and he just dismissed that. Between that and the next guy I saw it was frustrating. Very frustrating. And as a result of that I got very involved with the Lupus Foundation of America, now I guess there's lots of	1. My experience with SLE has been helpful to others in my life. 2. I believe that my experience with SLE has helped others manage their own experience with SLE. 3. I use what I have learned through my experience with SLE to help others in my daily life.

	<p>them and I became president of the local chapter (Laura, MAXQDA 12).</p> <p>We have an UNBELIEVABLE network of friends who really is more my family than anything who also is very very involved. Right now for instance we're getting ready for the annual lupus walk with our network of friends, there's about fifty of us that come to it every year. So (Monica, MAXQDA 22).</p>	
Sub-Theme 2: SLE is a part of who they are	<p>We're not keeping up appearances kind of people I think in any aspect of our lives. It is what it is. And the other thing was that you know personally, the whole guilt factor, the whole I guess Type A personality physician, I guess you want to do the best, be the best. Um, something like this is a big kick in the teeth and so for me, being very open especially because you LOOK totally normal having lupus, being very open about it has kind of, it was important for me for people to try to understand that hey listen, I haven't all of a sudden gotten bitten by the lazy bug. This is what's going on. You know I've never felt that there was any shame in it. It was more I guess I felt better about them understanding it as best as they could what I am going through because maybe they would understand why I can't keep to the same regimens that I used to (Monica, MAXQDA 24).</p>	4. I feel that my experience with SLE has helped me become who I am.
SLE Narrative Plot Line 4: Contaminated Life-As-Normal (4 participants)		

<p>Sub-Theme 1: Desire for normalcy in tension with family members' desire for normalcy</p>	<p>But I don't find that he's supportive in helping explain something to his family, to other people. It's not like, well, she can't do this because it REALLY does make her sick. He's just like, well she can't do it. I wish he was more supportive, again, I think people just don't want to hear it, oh okay, she's sick. But I think if he backed me up, it would make it more believable? (Melissa, MAXQDA 26)</p> <p>So the negative conversation was "well for God's sakes you're not dying!" When the reality was that I could have. And I was fortunate that I knew what to do and get to the hospital quickly. And I took some Benadryl before I left and I did everything to slow this reaction down. You know, but that was the comment. So there's a recent negative one. Where I was just like why would you even say that. You know you're not dying. Well yeah, I'm glad I didn't die but you know what, the next person with or without lupus could have died. It's a lack of sensitivity (Dierdre, MAXQDA 80).</p> <p>At one point, at one point, my husband did say. I was searching and searching and searching for something to help me. And he told me to stop. He said this is what you have, it's not gonna get better and deal with it. And this was 5 years ago. So I was 46 and I said, I'm too young, and I gotta do this, nobody else will help me, so, it was very unsettling (Evelyn, MAXQDA 12).</p>	<ol style="list-style-type: none"> 1. I feel that my family members have a different idea of what normal is with SLE. 2. I feel like my efforts to live normally with SLE are not well understood by my family members. 3. There is tension in my family about how to live with SLE.
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Sub-Theme 2: Perception that family members are tired of hearing about SLE	I think though after a year and a half, I think everyone kind of gets a little tired of you of me being not up to you know part of it is age I think too. I think yeah, they get a little bit tired of hearing I don't feel good, or its tough for me, or doing some of the things I used to do which was great hiking out in the sun and that and I know I don't do to the extent because I know I'll pay for it either with a couple of days of exhaustion or another flare up of another episode. So, its kind of a drag. I think, and You know they KNOW, but again I think the novelty of it has worn off and this is the way life is and its kind of a drag (Melissa, MAXQDA 22).	4.I feel like my family members are tired of talking about SLE.
Sub-Theme 3: Perception that family doesn't understand them.	With my sister when she was on vacation with me and I had said to her that I'm on medication that I'm not able to do this or like um, a lot of house projects, or maybe I'm not initiating something. And all I can say is she did not get it. And so, we had a conversation when I started to say to her really, I cannot do this, I just physically cannot do it. And I started to say that to her ahead of time and like I would say that and she just didn't get it (Allison, MAXQDA 24).	5. I often feel like my family minimizes my symptoms.
SLE Narrative Plot Line 5: Contaminated Restitution (2 participants)		

<p>Sub-Theme 1: Focus is on what was lost to SLE</p>	<p>That I had a great career I was working, everything in my life was going well. All of a sudden I started getting sick. Had a gall bladder surgery was diagnosed with pancreatitis. And then after the gall bladder was removed, I felt better, I went back and worked again, and started having joint swelling, extreme fatigue. And just by chance told my doctor about it and I had been kind of ignoring it and thinking I might have had a little arthritis. He said I want to see these spots that your getting these rashes, and I said okay, and I showed him and they diagnosed me with lupus pretty quick and he sent me to a rheumatologist I worked for 2 more years after that until I was unable to function (Amber, MAXQDA 7).</p>	<p>1. I had to quit many of the things that I did before I was diagnosed with SLE (working, active life style).</p>
<p>Sub-Theme 2: Managing identity shift from illness is a struggle in family relationships</p>	<p>You know there's only so much energy I have at the beginning of the day and really sometimes I want to work and I can't work and I get up and sit at the computer and a whole day goes by and I haven't done anything. And I'm not having pains that day, but I'm just tired. That's the hardest fatigue because you can't see the fatigue, there's nothing to test for fatigue. And so that's the hardest thing and maybe the reason it's hard for me to communicate that as well is because I have a fear of being seen as lazy, just un-motivated. Because I've never been that way before, it's just REALLY really hard for me (Stephanie, MAXQDA 22).</p>	<p>2. I feel like others see me as lazy because I can no longer do things the way I did before I got SLE.</p>

Sub-Theme 3:Continued expectation of recovery despite recognition of chronicity	So it changed my life completely. I had to quit working, I had to go on disability which was really hard for me. It still is hard. I keep thinking I might be able to go back, but I know I can't physically do it. So it's been life altering (Amber, MAXQDA 7).	3. I get frustrated with myself when I cannot do the things I did before getting SLE. 4. I keep thinking that I might be able to go back to work and/or to live my life the way I did before I got SLE, though I do not see this as a realistic goal.
Sub-Theme 4: Fighting through continual set backs	Currently I'm doing consulting because of a lot of reasons and it seems like I remain in consulting particularly because of my condition. Realistically it's impossible for me to be back at full time work given what's been happening and um even though I do them, consulting is more than full time work in some instances and my doctors tell me I'm taking on a bit too much. Essentially I am a consultant. Yes, and then recently, just like a few weeks ago I actually had to stop them because I had lupus nephritis flare up again, and so I had to take some time off. I couldn't handle that and the consulting at the same time. So it started to get a bit much for me (Stephanie, MAXQDA 2).	5. I continue to fight for recovery from SLE despite my continued struggle with complications and flares from the disease.
SLE Narrative Plot Line 6: Redemptive Quest (2 Participants)		

<p>Sub-Theme 1: Focus on using experience with SLE to change social perceptions of the disease</p>	<p>A good conversation was with senior staffer at the White House, and I brought my family to Washington DC and sat down and went to the white house to educate them, and you tell them what chronic illness is like and autoimmune disorders to show them what families go through. And it was a positive experience for my family because my kids felt like they were doing something actionable, and my husband felt like he was doing something that was actionable, I felt like I was doing something that was actionable and we felt like we were taking control (Bertha, MAXQDA 45).</p>	<p>1. I see my experience with SLE as an opportunity to change the way society views SLE and chronic illness. 2. I see my experience with SLE as a chance to educate society about suffering in illness.</p>
<p>Sub-Theme 2: Use experience with SLE to educate the public on a large scale about SLE (not just in everyday interaction)</p>	<p>Yes, and my husband accompanies me and on speaking engagements when he can, when he can he talks like I do my presentation, I've done it several times at MUFC for family and friends of lupus and I usually get him to give his perspective and answer questions and he stays until I'm on it (Elise, MAXQDA 34).</p> <p>Yeah, I wrote it [a book] with a colleague of mine from Clemson University and she had scleroderma. And it's a very positive, not pollyanish, but it just helps people cope and deal with all the emotional and other aspects of it (Elise, MAXQDA 28).</p>	<p>3. I have taken steps toward enacting social change because of my experience with SLE. 4. I see my experience with SLE as a chance to teach others in our society living with SLE how to live better in illness.</p>

In sum, a total of 27 items were created to measure the six narrative plotlines that emerged in Study 1. In order to assess the validity of the items created for each plotline, I conducted a Principle Components Analysis (PCA) with varimax rotation on all 27 items used to measure the plot lines. The PCA resulted in a seven-factor solution which accounted for 64.67% of the overall variance. Using the 60/40 rule, the seven factor solution indicated inconsistent loadings on several items, including ambivalent life-as-normal items 2 and 3, ambivalent quest item 2, and contaminated restitution items 4 and 5 (see Table 3). Based on their poor loadings, these items were removed from the scale and I conducted a second Principle Components Analysis on the remaining items.

The initial unrotated PCA yielded four eigenvalues greater than one and accounted for 59.25% of the variance. A scree plot confirmed the four-component solution. Following rotation, each component was assessed for loadings using the 60/40 rule, which resulted in a four-factor solution that suggested the need to combine ambivalent chaos and contaminated restitution because they loaded on the same factor. It also suggested the need to combine ambivalent quest and redemptive quest items, which also all loaded on the same factor. Both an examination of the meaning (see Table 4) of each of these items and a reliability analysis combining items that loaded on the same factor further confirmed this choice. Specifically, alpha reliabilities on the ambivalent chaos items plus the contaminated restitution items were very good ($\alpha = .85$), justifying the combination of these items into a single SLE narrative plotline, renamed “Chaotic.” Similarly, the combination of ambivalent and redemptive quest items were reliable ($\alpha = .86$) and were therefore combined and the plotline was renamed “Quest.” Although the reliability for the ambivalent life-as-normal items was relatively low ($\alpha = .61$), all three

items loaded clearly on the same factor (see Table 4) and were therefore retained.

Similarly, all the contaminated life-as-normal items clearly loaded on the same factor and had a high reliability at .88. Thus, the six SLE narrative plotlines that emerged in the qualitative data collection and analysis conducted for Study 1 were condensed to four SLE narrative plotlines based on the quantitative data collection and analysis conducted for Study 2. Thus, the SLE narrative plotlines that were used in the data analysis for Study 2 were the chaotic SLE narrative plotline ($\alpha = .85$), the quest SLE narrative plotline ($\alpha = .86$), the ambivalent life-as-normal SLE narrative plot line ($\alpha = .61$), and the contaminated life-as-normal SLE narrative plotline ($\alpha = .88$). The items that loaded on each of these factors, respectively, were averaged to produce a composite score for each of the four plotlines (see Table 8 for descriptive statistics).

Table 3 Principle Components Analysis SLE Narrative Plotlines 7 Factor Solution

Items	1	2	3	4	5	6	7
Ambivalent Chaos							
1. Every day is a struggle with SLE.	.59	.18	.48	-.31	-.09	.13	.31
2. When I have symptoms it feels like they will go on forever.	.57	.20	.26	-.25	-.16	-.08	-.02
3. I have difficulty with all aspects of my life because of SLE.	.64	.22	.37	-.10	-.29	.23	-.02
4. I feel like I'm always waiting and wondering what's going to happen next.	.67	.04	.13	.12	-.12	-.21	-.11
Contaminated Restitution							
1. I had to quit many of the things that I did before I was diagnosed with SLE (working, active life style).	.58	.24	.21	-.31	-.22	.02	.18
2. I feel like others see me as lazy because I can no longer do things the way I did before I got SLE.	.67	.15	-.04	.17	-.21	.09	-.07

1. My experience with SLE has been helpful to others in my life.	-.44	.41	-.11	.10	-.03	.53	.05
2. I feel that my experience with SLE has helped me become who I am.	-.12	.40	.04	.45	-.30	.14	-.34
3. I believe that my experience with SLE has helped others manage their own experience with SLE.	-.28	.58	-.09	.01	-.24	.09	.32
4. I use what I have learned through my experience with SLE to help others in my daily life.	-.35	.73	-.12	-.02	.09	.07	.20
Redemptive Quest							
1. I see my experience with SLE as an opportunity to change the way society views SLE and chronic illness.	-.35	.78	-.08	-.04	-.02	-.07	-.06
2. I see my experience with SLE as a chance to educate society about suffering in illness.	-.29	.74	-.11	-.20	-.10	-.15	-.09
3. I see my experience with SLE as a chance to teach others in our society living with SLE how to live better in illness.	-.36	.74	-.14	-.03	-.06	-.11	.11
4. I have taken steps toward enacting social change because of my experience with SLE.	.00	.61	-.02	-.10	-.23	-.23	-.40

Table 4 Principle Components Analysis for SLE Narrative Plotlines 4 Factor Solution

Items	1	2	3	4
Ambivalent Chaos				
1. Every day is a struggle with SLE.	-.10	.11	.80	.10
2. When I have symptoms it feels like they will go on forever.	-.01	.19	.72	-.01
3. I have difficulty with all aspects of my life because of SLE.	-.04	.25	.77	.11
4. I feel like I'm always waiting and wondering what's going to happen next.	-.20	.44	.51	.12

Contaminated Restitution				
1. I had to quit many of the things that I did before I was diagnosed with SLE (working, active life style).	.05	.18	.68	-.08
2. I feel like others see me as lazy because I can no longer do things the way I did before I got SLE.	-.07	.54	.43	-.05
3. I get frustrated with myself when I cannot do the things I did before getting SLE.	-.06	.41	.51	-.24
Ambivalent Life-As-Normal				
1. I have accepted SLE is a normal part of my life.	.26	-.08	-.23	.73
4. I've accepted that SLE is here to stay.	-.03	.01	.17	.74
5. I've accepted that I will just have to roll with what SLE throws my way.	.02	-.02	.03	.76
Contaminated Life-As-Normal				
1. I feel that my family members have a different idea of what normal is with SLE.	-.04	.74	-.02	-.05
2. I feel like my efforts to live normally with SLE are not well understood by my family members.	-.14	.80	.27	-.04
3. I feel like my family members are tired of talking about SLE.	-.10	.78	.23	-.06
4. I often feel like my family minimizes my symptoms.	-.01	.85	.19	.08
5. There is tension in my family about how to live with SLE.	.02	.72	.30	-.02
Ambivalent Quest				
1. My experience with SLE has been helpful to others in my life.	.54	-.10	-.29	.03
3. I believe that my experience with SLE has helped others manage their own experience with SLE.	.67	-.06	-.02	.05
4. I use what I have learned through my experience with SLE to help others in my daily life.	.79	-.01	-.12	.05
Redemptive Quest				

1. I see my experience with SLE as an opportunity to change the way society views SLE and chronic illness.	.86	-.06	-.05	.09
2. I see my experience with SLE as a chance to educate society about suffering in illness.	.82	-.11	.05	.04
3. I see my experience with SLE as a chance to teach others in our society living with SLE how to live better in illness.	.83	-.05	-.10	.07
4. I have taken steps toward enacting social change because of my experience with SLE.	.57	.03	.28	-.00

SLE Family Myth Variable

As discussed in Chapter 4, upon coding SLE narrative plot lines and dominant family communication behaviors to each individual case, three distinct SLE family myths emerged in the cross case data matrix analysis conducted in Study 1. Thus, I created the SLE family myth variable by constructing narrative descriptions of each category based on the themes and sub-themes around which the three categories of the SLE family myth variable clustered (Song, Lin, Ward, & Fine, 2013). Wherever possible, I employed specific participant language in the narrative description to reflect each category (Creswell & Plano Clark, 2011).

Measure of SLE family myths. The SLE family myths that emerged in the cross case data matrix analysis and described in the write up of the qualitative results were integrated into Study 2 through the process of data transformation and integration (Fetters et al., 2013). This process consisted of the identification of within each SLE family myth that were reflected in specific participant quotes. These were then transformed into the overall narrative description of each SLE family myth (See Table 5). This yielded a

categorical variable that described distinct perceptions of family in relation to SLE (i.e. SLE family myth) and was measured by asking participants to choose which narrative description best describes their perception of their family in relation to their SLE.

Table 5 Joint Display of SLE Family Myth Categorical Variable Creation

Sub Themes	Representative Quotes	Narrative Description
Harmonious SLE Family Myth (15 participants)		
Sub-Theme 1: Individual with SLE feels supported by family in managing SLE	I have seen him take time off work to stay home and be with me. When I was at my worst with the fever, and it was so cold and I couldn't get warm. He would start a fire and a kerosene heater and basically bake me all day long. By the time he got home everything was dying down and he would crank it out again. He was very supportive that way and has been all along (Nicole, MAXQDA 28).	My family supports my experience with SLE. They talk openly about the illness with me and I feel comfortable discussing it when I want to discuss it. My family regularly expresses their concern for my well-being and seeks out and/or are open to learning about the disease. My family works with me to manage SLE.
Sub-Theme 2: Family openness about SLE	I would be hard pressed to come up with ONE conversation that was particularly good or bad. Because there's been lots of smaller conversations that have gone on (Sarah, MAXQDA 43)	
Sub-Theme 3: Family expressed concern for health and well-being of individual with SLE	"And he [her spouse] said, "I really hate to see you going through this". And I knew that he actually understood it and meant it" (Angie, emphasis in the original, MAXQDA 33)	
Sub-theme 4: Family seeks out information about SLE	I've not been in the dating world, I'd been married for 28-29 years this was casual, but for some reason I just said, you know I have lupus and he started asking questions and so I said there's something I can give you to read and it was from NIH and it was for patients and families	

	and I thought that will be the end of it. He won't read it or anything, but at least I told him. But he came back and he had read it. And asked questions and he does that now. He'll pick up lupus magazine and read an article and ask questions (Elise, MAXQDA 54).	
Sub-theme 5: Individual with SLE perceives family as working with her to manage the disease	So he's you know, he's learned a lot and it's kind of like we have lupus as opposed to I have lupus" (Shannon, MAXQDA 8)	
Abandoned SLE Family Myth (7 participants)		
Sub-theme 1: Individual with SLE feels alone in managing the disease.	It's kind of a lonely feeling actually (Celeste, MAXQDA 18)	I feel alone in managing SLE. My family members avoid talking with me about it and I don't feel as if I can initiate discussions about SLE with them. I feel that my family members don't believe that I have SLE, or, if they do, they don't believe that it is a struggle for me to manage it. My family members do not seem concerned for me as I manage this disease.
Sub-theme 2: Family avoids discussions about SLE.	Well I can't talk to my brother and my sister, they just don't want to hear about it. It's like, tell me everything is wonderful (laugh) (Amy, MAXQDA 10).	
Sub-theme 3: Individual with SLE feels unable to initiate discussions about SLE in her family.	And I pretty much accepted that no one wants to hear about woah is me, it gets old (Joan, MAXQDA 22).	
Sub-theme 4: Individual with SLE perceives that family members do not believe that she has the disease and/or that she struggles because of it.	My sister pretty much acts like I'm just making it up to try to get attention or something (Celeste, MAXQDA 12).	

Sub-theme 5: Individual with SLE perceives that her family members are not concerned for her well-being in managing SLE.	And even if I'm at my daughter's house or something and I have the rash or I have a bad headache, they just say "oh that's too bad" you know and then they change the subject (Celeste, MAXQDA 18).	
Battle SLE Family Myth (6 participants)		
Sub-theme 1: Individual with SLE perceives tension in her family about SLE.	<p>So, he made a remark about being the only one, having to wanting to review who I gave money to because after all I wasn't working. And it just pissed me off. So it had more to do with the consequences of dealing with the disability than it did about specifically about lupus or the physician's appointment. He does think, we've had conversations about the amount of drug that I still take. And he just kind of made it clear that he would not do that (Allison, MAXQDA 28).</p> <p>I think the times when I've had to defend myself when I've had to explain that, no it's not that I don't like you and it's not that I don't want to have fun playing cards with the family, it's just that I don't have the energy (Melissa, MAXQDA 34).</p>	I feel tension with my family members about my SLE. I feel like my family and I are at odds with our expectations for managing this disease (e.g., a focus on recovery as opposed to a focus on disease management and/or quality of life with an illness that is not curable). I am not able to talk openly in my family about SLE because I get the feeling that they are tired of hearing about it.

<p>Sub-theme 2: Individual with SLE perceives that her family disagrees with her about how to manage the disease.</p>	<p>Well one of my sons just said you just need to get up. He made a food plan for me and an exercise for me. You just need to push through this Mom. I'm a single mom and I raised my kids by myself so they've seen strength. So they said "you can do this, you can push through this I know you can I've seen you". And I'm like, I can't even get up to go to the bathroom. I'm not doing any exercises. And it felt very difficult for them to accept. You know one day my Son said finally, would you just try. I worked out these stretches for you and I said "I'll try" and when he saw how difficult it was for me to do the stretches, he was like "wow"(Amber, MAXQDA 29).</p>	
<p>Sub-theme 3: Individual with SLE is not able to talk openly about SLE because she perceives her family is tired of hearing about SLE.</p>	<p>I think though after a year and a half, I think everyone kind of gets a little tired of you of me being not up to you know part of it is age I think too. I think yeah, they get a little bit tired of hearing I don't feel good, or its tough for me, or doing some of the things I used to do which was great hiking out in the sun and that and I know I don't do to the extent because I know I'll pay for it either with a couple of days of exhaustion or another flare up of another episode. So, it's kind of a drag. I think, and you know they KNOW, but again I think the novelty of it has worn off and this is the way life is and it's kind of a drag (Melissa, MAXQDA 22)</p>	

<p>Sub-theme 4: Family members over-emphasize the disease</p>	<p>They talk about it, they tell people my mom has lupus and my mom is really sick, I mean they've talked about it with friends and family I live in a small community and I think everybody in town knows I have it because my kids have told everybody. You know. And me, on the other hand, I didn't want everybody to know (Amber, MAXQDA 13).</p>	
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Measures of Dependent Variables

Though the independent variables in Study 2 were the result of the integration process, the dependent variables are, for the most part, established measures. For example, the confirmation/disconfirmation measure, openness/avoidance measure, family satisfaction, physical and mental health measures have all been used in previous research. The self-management behavior measure was developed specifically for this study.

Measure of Confirmation/Disconfirmation

Perspective-taking is the degree to which individuals attend to and confirm one another's experiences (Koenig Kellas et al., 2010). Given that many participants in Study 1 experienced the absence of a family members' acknowledgement of SLE and its implications on their lives as disconfirming, I determined that operationalizing confirmation in terms of both attentiveness and confirmation (i.e. perspective taking) would be the best approach. Thus, Koenig Kellas, Willer & Trees' (2013) communicated perspective taking scale was used to measure confirmation/disconfirmation. This 19-item 5-point Likert scale asks participants to rate the degree to which they agree or disagree (1=strongly disagree, 5=strongly agree) with statements about communication in their families (see Appendix B). Sample items include "My family members are disengaged (do not pay attention) during our interactions about the systemic lupus" and "My family members do not do a good job acknowledging my experience with systemic lupus". This scale was modified to specifically measure family communication about SLE (e.g., "My family is attentive to me during conversations about systemic lupus"). Items 3, 6, 9, 12, 15, and 19 were reverse coded such that higher scores for all the items reflected higher

levels of communicated perspective taking (i.e. confirmation). The items were averaged together in order to score the scale and, for this study, the reliability was high at .95.

Measure of Openness/Avoidance

Openness and avoidance were operationalized using a modified version of the openness section and avoidance section of Caughlin's (2003) family communication standards instrument. The openness portion of this scale is a 7-item Likert-type scale asking participants to indicate their level of agreement with items (i.e., 1=strongly agree, 7=strongly disagree) and has yielded a reliability of .88 and .90 in previous research (Rubin, Rubin, Graham, Perse, & Siebold, 2011). Sample items include "People in my family can talk openly to one another about SLE" and "People in my family share SLE related problems with each other". The original avoidance portion of the scale is a two-item Likert-type scale ("People in my family avoid talking about SLE"), though I modified these items and added one item to tease out avoidance of information about SLE and avoidance about medical information, physical struggles, emotional struggles related to SLE management based on the qualitative findings as well as the extant literature (e.g., "People in my family avoid talking about the emotional struggle of SLE" and "People in my family avoid talking about the medical implications of SLE"). The avoidance section has a reliability between .80 and .88 (Rubin et al., 2011). In order to meet the needs of this study, the scale was modified from a measure of the ideal family to a measure of participants' specific families and the items were tailored specifically to openness and avoidance about SLE (e.g., people in my family can talk openly with one another about SLE; people in my family avoid talking about the emotional struggle of SLE). In order to score this scale, the three items that measured avoidance (items 8, 9,

and 10) were reverse coded so that higher scores on each of the items in the scale reflected more openness. Thus, for this study, the scores for each item were averaged in order to understand the degree of openness about SLE in family relationships ($\alpha=.92$).

Measure of Physical and Mental Health and Well-Being

Physical and mental health and well-being were operationalized using the SF-36 Measures Quality of Life in Illness through physical, mental health and comes from the Medical Outcomes Study (Stewart & Ware, 1992). The SF-36 is a widely used generic measure of physical and mental health and well-being with 36 items. Physical health is measured using four scales (physical functioning, role-physical, bodily pain, and general health). Sample items include “During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?” Participants are asked to rate items such as “Cut down on the amount of time you spent on work or other activities” and “Accomplished less than you would like” on a 5 point Likert-type scale ranging from “All of the time” to “None of the time.” There is one section on physical health that uses a 3 point Likert-type scale asking respondents to rate their ability to perform daily activities. This section was removed because the questions are redundant with the rest of the scale and the 3 point Likert-type scale unnecessarily complicates scoring as all other items are measured on a 5 point Likert-type scale. Thus, for this study, physical health was measured by averaging scores on an 11 item, 5-point Likert scale specific to physical health with higher scores reflecting better physical health ($\alpha=.90$).

Mental health is measured using four scales (vitality, social functioning, role-emotional, and mental health). These are all measured on a five point Likert-type scale,

with sample items including “These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling”. “Did you feel full of life” or “Have you had lots of energy?” or “Have you felt calm and peaceful?” Reliability estimates for physical and mental summary have typically exceeded 0.90 (Ware, Kosinski, & Keller, 1994). For this study, mental health was measured by averaging the scores on the 14 items related to mental health whereby higher scores reflect better mental health ($\alpha=.91$).

Measure of Family Satisfaction

Family satisfaction was operationalized using Huston, McHale, & Crouter’s (1986) Marital Opinion Questionnaire (see Appendix B). This scale was modified to measure satisfaction with family relationships, similar to Afifi and Schrodt’s (2007) modification of this scale for use in family relationships that had a reported Cronbach’s alpha score that ranged between .93 to .97. The measure itself is an 11 item scale, with 10 items on a seven-point semantic differential scale (e.g. Miserable-Enjoyable and Rewarding-Disappointing) and one item that rates global satisfaction with one’s family ranging from *completely dissatisfied* (1) to *completely satisfied* (7). Per Huston et al.’s recommendations, the measure was scored by first dropping two of the items (free-tied down and hard-easy), reverse coding items 2, 5, 6, and 10, then averaging the remaining eight semantic differential items ($\alpha=.93$). This total was then averaged with the score of the global item resulting in a family satisfaction average in which higher scores reflect higher levels of family satisfaction.

Measure of Self-Management Behavior

Despite the clear importance of self-management behavior in the context of systemic lupus, most measures of self-management focus specifically on medication adherence in general (Bailey, Oramasionwu, & Wolf, 2013) or dietary/lifestyle management in the context of diabetes (Rosland et al., 2012). According to Wallace (2008), effective management of SLE includes a combination of lifestyle choices (managing sun exposure, getting plenty of rest, and exercise), medication adherence, regular appointments with physicians, and following treatment recommendations offered by medical professionals (Wallace, 2008). Guided by Wallace's (2008) description of the experience and management of SLE, a 7-point Likert type scale was created for this study in order to measure self-management behaviors specific to systemic lupus. The scale is designed to manage three of the most critical elements of self-management in SLE (lifestyle, treatment plan adherence, and regular physician visits) (see Appendix B). Though reliability was acceptable at .75, because this scale was developed specifically for this study, I again ran a Principle Components Analysis on all 12 items to determine the viability of each scale item. Though the initial unrotated PCA yielded four eigenvalues greater than one and accounted for 67.29% of the variance (See Table 6), examination of the scree plot indicated the existence of a two-component rather than a four-component solution. An examination of item loadings revealed that Items 10 (I consistently get infusions when my physician recommends this course of treatment) and 11 (I undergo surgeries when my physician recommends this course of treatment) were the only items that loaded on the second factor. Examination of the items indicate that they were not applicable to a large portion of the population as SLE patients who require infusions and surgery likely have organ involvement. This accounts for 59% of this

sample, making this question irrelevant for at least 41% of the sample. Further, those with organ involvement do not always require infusions or surgery. It is likely that these two questions were not relevant for a majority of this sample. Based on this, items 10 and 11 were removed from the analysis and the Principle Components Analysis was run a second time, resulting in three components with eigenvalues greater than one (See Table 7). Again, closer examination of the scree plot indicated a two-component solution. Further examination of the scale items indicated the items centered around two constructs: general compliance and communication with physician. Thus, items were grouped accordingly and reliability analyses were run on the items that comprised these two categories of self-management. Physician communication was comprised of items 5, 6, 7, and 8 (e.g., I maintain a regular appointment schedule with my physician, I communicate new or unusual symptoms to my physician) and had a good reliability at .80. General compliance was comprised of items 1, 2, 3, 4, 9, and 12 and centered on general self-management behaviors specific to SLE (e.g., I avoid sun exposure, I strive to get enough rest to manage my condition). General compliance had acceptable reliability at .73.

Table 6 Principle Components Analysis for Self-Management Behavior 4 Factor Solution

Items	1	2	3	4
1. I avoid sun exposure and wear sunscreen when I am in the sun.	.62	-.01	.20	-.14
2. I strive to maintain a healthy, balanced diet.	.31	-.01	.72	-.04
3. I strive to exercise within my capabilities regularly.	-.03	.24	.79	-.09
4. I strive to ensure I get enough rest to manage my condition.	.12	.11	.74	.22
5. I maintain a regular appointment schedule with physician.	.50	.64	.14	.11

6. I communicate new or unusual symptoms to my physicians.	.51	.64	.11	.15
7. I discuss the impact of disease on my life with physicians.	.17	.86	.10	.00
8. I discuss barriers to care with my physicians.	-.06	.82	.12	-.08
9. I regularly take all medications prescribed by my physician to manage SLE.	.82	.20	.08	.16
10. I consistently get infusions when my physician recommends this course of treatment.	.10	.08	-.03	.79
11. I undergo surgeries when my physician recommends this course of treatment.	.02	-.06	.09	.82
12. I generally follow my physicians' treatment recommendations to manage SLE.	.84	.20	.06	.16

Table 7 Principle Components Analysis Self-Management Behavior 3 Factor Solution

Items	1	2	3
1. I avoid sun exposure and wear sunscreen when I am in the sun.	.55	-.01	.23
2. I strive to maintain a healthy, balanced diet.	.29	-.01	.72
3. I strive to exercise within my capabilities regularly.	-.05	.25	.79
4. I strive to ensure I get enough rest to manage my condition.	.16	.08	.74
5. I maintain a regular appointment schedule with physician.	.55	.60	.14
6. I communicate new or unusual symptoms to my physicians.	.57	.61	.11
7. I discuss the impact of disease on my life with physicians.	.20	.87	.09
8. I discuss barriers to care with my physicians.	-.05	.83	.12
9. I regularly take all medications prescribed by my physician to manage SLE.	.85	.16	.08

12. I generally follow my physicians' treatment recommendations to manage SLE.	.87	.17	.07
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CHAPTER EIGHT

STUDY 2 RESULTS

Descriptive Statistics

Descriptive statistics were run to ensure the normalcy of the data and are presented in Table 8. Stem and leaf plots were examined to determine outliers on any of the study variables. One participant (participant 67) emerged as an outlier on three variables in that she reported significantly less suffering, better physical health, and better mental health than the rest of the sample. Thus, she was removed from the analysis. Further, nine participants (35, 37, 38, 40, 53, 99, 132, 157, 159) completed the survey but had received their SLE diagnosis within 12 months of completing the survey and thus did not meet the inclusion criteria for the study (all participants were required to have been diagnosed at least 12 months before completing the survey) and were removed from the analysis. This, then, resulted in a sample size of 112 participants. Although the power analysis indicated a need for 120 participants, the sample size of 112 was sufficient in finding statistically significant relationships between the independent and dependent variables in this analysis.

Table 8: Descriptive statistics

Variables	Mean	SD	Alpha
*Degree of Suffering	5.51	1.40	n/a
*Family Satisfaction	4.51	1.39	.93
*Physical Health	2.26	.76	.90
*Mental Health	2.73	.75	.91
*Perspective Taking	3.29	.94	.95
*Openness	4.23	1.44	.92
*Ideal Openness	6.40	.67	.90
*General Compliance	5.37	.98	.73
*Physician Communication	5.45	1.43	.80
Ambivalent Life-As-Normal NPL	4.23	.73	.61
Contaminated Life-As-Normal NPL	3.20	1.14	.88
Chaotic NPL	3.90	.88	.85
Quest NPL	3.63	.79	.86

**Dependent Variables*

Table 9: Correlation matrix for all study variables

	Chaotic NPL	Quest NPL	Ambival ent LAN NPL	Cont LAN NPL	Fam Sat	Phys Health	Mental Health	P- Taking	Opennes s	Gen Complia nce	Phys Comm
Chaotic NPL	1.00	-.06	-.01	.61**	-.41**	-.72**	-.68**	-.39**	-.36	-.05	-.02
Quest NPL		1.00	.15*	-.09	.19*	.15*	.18*	.15	.19*	.20*	.12
Amb LAN NPL			1.00	-.05	.06	-.08	.01	.03	.07	-.03	-.07
Cont LAN NPL				1.00	-.66**	-.36**	-.55**	-.74**	-.71**	-.14	-.12
Fam Sat					1.00	.41**	.54**	.72**	.66*	.15*	.03

Phys	1.00	.69**	.27**	.22**	.06	.05
Health						
Mental		1.00	.51**	.52**	.08	.08
Health						
P-			1.00	.78**	.10	.13
Taking						
Openness				1.00	.21**	.18*
s						
Gen					1.00	.50**
Compliance						
Phys						1.00
Comm						

* $P < .005$, ** $P < .001$

Data Analysis

The first four research questions posed in this study were focused on understanding the extent to which the four SLE narrative plotlines (i.e. the chaotic narrative plotline, the quest narrative plotline, the ambivalent life-as-normal narrative plotline, and the contaminated life-as-normal narrative plotline) and family communication behaviors (i.e. openness/avoidance, confirmation/disconfirmation) predicted the dependent variables of interest. Thus, in order to answer the first four research questions posed in this study, I ran a series of multiple regressions using SPSS statistical software. In order to answer the fifth research question, I ran a series of MANOVAs given that the initial descriptive statistics indicated correlation between several of the dependent variables.

RQ1: SLE Narrative Plotlines, Family Communication, and Physical Health

Research question 1 asked how SLE narrative plotlines (i.e. the chaotic narrative plotline, the quest narrative plotline, the ambivalent life-as-normal narrative plotline, and the contaminated life-as-normal narrative plotline) and family communication behaviors (i.e. openness/avoidance, confirmation/disconfirmation) predict physical health. A multiple regression was run, resulting in a significant model $F(6, 109) = 23.12, p < .001$. Examination of beta weights (see Table 10) revealed that the chaotic narrative plotline was the only significant predictor ($\beta = -.78$) of physical health, suggesting that the more chaotic the narrative plotline, the less physically healthy the person (See Table 10).

Table 10: Predictors for Physical Health

Predictors	Beta	p

Perspective-Taking	.07	.55
Openness in Family about SLE	-.07	.53
Chaotic SLE Narrative Plotline	-.78	.00
Quest SLE Narrative Plotline	.06	.39
Ambivalent Life-As-Normal SLE Narrative Plotline	-.08	.21
Contaminated Life-As-Normal SLE Narrative Plotline	.10	.41

RQ2: SLE Narrative Plotlines, Family Communication, and Mental Health

Research question 2 asked how SLE narrative plotlines and family communication behaviors predict mental health. Results of the multiple regression indicate a significant model for mental health $F(6, 109) = 24.62, p < .001$. Examination of beta weights (see Table 11) indicate that openness about SLE is a significant predictor for the mental health of women with SLE ($\beta = .27$). Further, the chaotic narrative plotline was negatively correlated with mental health ($\beta = -.55$). This suggests that the more open families are in their communication about SLE, the better the mental health of the woman with SLE. Further, the more chaotic a woman's SLE narrative plotline is, the poorer her mental health (see Table 11).

Table 11: Predictors of Mental Health

Predictors	Beta	p
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Perspective-Taking	.01	.96
Openness in Family about SLE	.27	.02
Chaotic SLE Narrative Plotline	-.55	.00
Quest SLE Narrative Plotline	.07	.30
Ambivalent Life-As-Normal SLE Narrative Plotline	-.03	.67
Contaminated Life-As-Normal SLE Narrative Plotline	-.03	.80

RQ 3: SLE Narrative Plotlines, Family Communication, and Family Satisfaction

The third research question posed in this study asked how SLE narrative plotlines (i.e. the chaotic narrative plotline, the quest narrative plotline, the ambivalent life-as-normal narrative plotline, and the contaminated life-as-normal narrative plotline) and family communication behaviors (i.e. openness/avoidance, confirmation/disconfirmation) predict family satisfaction. The model was significant $F(6, 106) = 22.47, p < .001$. Communicated perspective taking as a form of confirmation was the only predictor that emerged as significant ($\beta = .42$), suggesting that increased communicated perspective-taking as a form of confirmation is correlated with increased family satisfaction (all beta weights are reported in Table 12).

Table 12: Predictors of Family Satisfaction.

Predictors	Beta	p
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Perspective-Taking	.42	.00
Openness in Family about SLE	.12	.30
Chaotic SLE Narrative Plotline	-.12	.15
Quest SLE Narrative Plotline	.05	.45
Ambivalent Life-As-Normal SLE Narrative Plotline	.05	.44
Contaminated Life-As-Normal SLE Narrative Plotline	-.17	.17

RQ 4: SLE Narrative Plotlines, Family Communication, and Self-Management Behavior

The fourth research question posed in this study asked how SLE narrative plotlines and family communication behaviors predict self-management behavior. Based on the results of the PCA, self-management behavior was measured in terms of communication with physician. Thus, a multiple regression was run resulting in a non-significant model for physician communication $F(6, 105) = .975, p = .446$ as well as for general compliance $F(6, 106) = 1.69, p = .130$. Thus, there were no significant predictors of self-management behavior (see Table 13).

Table 13: Predictors of Self-Management Behavior

Predictors	<i>General Compliance</i>		<i>Physician Communication</i>	
	Beta	p	Beta	P
Perspective-Taking	-.31	.09	-.11	.56
Openness in Family about SLE	.28	.09	.22	.20
Chaotic Narrative Plotline	.08	.52	-.01	.96
Quest Narrative Plotline	.14	.16	.08	.42
Ambivalent Life-As-Normal SLE NPL	-.08	.39	-.10	.29
Contaminated Life-As-Normal SLE NPL	.23	.12	-.06	.74

RQ 5: Implications of SLE Family Myths

RQ5 asked whether the three SLE family myths that emerged in Study 1 (i.e. harmonious, abandoned, and battle) could explain differences in physical and mental well-being, family satisfaction, and self-management behavior. The initial descriptive statistics indicated that some of the dependent variables were both conceptually similar and correlated with one another, indicating the need to run two separate MANOVAs to understand differences between groups on a series of conceptually similar and correlated dependent variables. Specifically, the three measures of physical (physical health), mental (mental health), and relational (family satisfaction) well-being were correlated with one another (see Table 14). General compliance and physician communication were conceptually related as components of self-management behavior and moderately correlated with one another. Thus, I ran a MANOVA examining the two components of self-management behavior (general compliance and physician communication...

Table 14 Correlations among dependent variables

	Fam Sat	Mental Health	Phys Health	General Compliance	Phys Comm
Fam Sat	1.00	.54**	.41**	.15	.03
Mental Health		1.00	.69**	.08	.08
Physical Health			1.00	.06	.05
Gen Comp				1.00	
Phys Comm					1.00

* $p < .005$, ** $p < .001$

Thus, the first one-way multivariate analysis of variance (MANOVA) was conducted to determine if the three distinct SLE family myths (harmonious, abandoned, battle) could explain differences in three dependent variables (physical health, mental health, and family satisfaction). The overall test was significant, Wilks $\Lambda = .60$, $F(6, 244) = 11.98$, $p < .01$. Univariate analyses of variances (ANOVAs) were run on these three dependent variables in follow up to the MANOVA. Using the Bonferroni method to protect against family-wise error, each ANOVA was tested at the .02 level of significance ($.05/3 = .02$). Two of the ANOVAs were significant: mental health $F(2, 124) = 9.88$, $p = .000$, $\eta^2 = .14$ and family satisfaction, $F(2, 124) = 37.61$, $p = .000$, $\eta^2 = .38$. However, the ANOVA on physical health was non-significant, $F(2, 1124) = 2.12$, $p = .124$, $\eta^2 = .03$.

Post hoc analyses to the univariate ANOVAs for the mental health scores and family satisfaction scores consisted of conducting pairwise comparisons to determine

which SLE family myth was most strongly correlated with each dependent variable (see Table 15). For the sake of consistency, pairwise comparisons were evaluated using the Bonferroni method. Results of this analysis suggest that those with the harmonious SLE family myth had better mental health and had higher levels of family satisfaction than those with either the abandoned or the battle SLE family myth. There were no significant differences between the abandoned and the battle SLE family myth on either of these dependent variables.

Table 15 SLE Family Myths Means and SDs

	Physical Health		Mental Health		Family Satisfaction	
	M	SD	M	SD	M	SD
Harmonious	2.39	.82	2.95	.76	5.16	.99
Battle	2.07	.62	2.40	.54	3.61	1.24
Abandoned	2.14	.57	2.30	.59	3.27	1.18

The second MANOVA was conducted to determine if the three SLE family myths (harmonious, abandoned, and battle) could explain differences in the remaining two dependent variables (communication with physician and general compliance) that together comprise our understanding of self-management behavior in SLE. No significant differences were found between the three SLE family myths $\Lambda = .954$, $F(4, 244) = 1.46$, $p = .216$. Since no significant difference was found, it was not necessary to conduct follow up analyses. Results, then, indicate that there are no differences in the self-management behavior (general compliance and physician communication) of women with harmonious, battle, and abandoned SLE family myths.

CHAPTER 9

STUDY 2 DISCUSSION

Like Study 1, Study 2 was grounded in CNSM, a conceptual model that both prioritizes the communicative nature of narrative sense-making and provides the theoretical structure to study and make connections between communicative patterns and health and well-being (Koenig Kellas & Kranstuber Horstman, 2015). Guided by this theoretical model, the purpose of Study 2 was two-fold. First, consistent with an exploratory sequential mixed methods project (Creswell, 2015), Study 2 was designed to integrate the findings from Study 1 into Study 2, and, in so doing, create a more nuanced representation of communicated narrative sense-making in SLE (i.e. SLE narrative plotlines and SLE family myths). Second, in order to better understand how family communication and narrative sense-making work in tandem to impact health and well-being in SLE, Study 2 was designed to determine if narrative sense-making and family communication behaviors specific to women with SLE were correlated with physical and mental health, family satisfaction, and self-management behavior. Thus, in what follows, I discuss the significance of the findings for Study 2 in relation to these two objectives. I follow this with a discussion of the limitations of Study 2. In the final chapter (Chapter 10), I discuss the significance of the findings of this mixed methods research project as a whole.

SLE-Specific Communicated Narrative Sense-Making Variables

The move in Study 2 to integrate qualitative findings by creating two new population specific variables that better represent the experience of women with SLE is important in facilitating research in SLE. Specifically, these variables reflect sense-

making processes specific to women managing SLE. Thus, these more nuanced variables represent an opportunity to both confirm the construct validity of each of these variables and conduct more nuanced research in order to better understand the unique experience of SLE. Further, the SLE family myth variable provides researchers with the ability to study communication as central to narrative sense-making processes.

SLE Narrative Plotlines Variable

The current study supports the utility of combining Frank's (1995, 2013) narrative types and McAdams' (1993) narrative tone into SLE narrative plotlines as a heuristic framework for understanding narrative sense-making in SLE. For example, the six SLE narrative plotlines that emerged in Study 1 were collapsed into four SLE narrative plotlines in analyzing the data for Study 2. Statistical analyses indicated the need to combine the contaminated restitution narrative plotline with the ambivalent chaos narrative plotline to form what became the chaotic SLE narrative plotline in Study 2. Similarly, the redemptive quest narrative plotline was combined with the ambivalent quest narrative plotline to form the quest narrative plotline for Study 2. Thus, the nuance gained in combining Frank's (1995, 2013) narrative types and McAdams' (1993) narrative tone in Study 1 bears out as an important distinction in the quantitative data analysis in Study 2, but with some modifications. This suggests the potential for future research to focus on testing the construct validity of this new variable specific to the experience of women with SLE through confirmatory factor analysis.

SLE Family Myth Variable

Building from McAdams' (1993) concept of the personal myth as an individual's identity that is narratively constructed between the self and the social world, the SLE family myth is a reflection of how SLE narrative plotlines and family communication work in tandem to shape how an ill individual perceives her family in light of her illness experience (e.g., supportive or unsupportive). Three distinct SLE family myths comprised of a unique combination of SLE narrative plotlines and family communication behaviors emerged in the cross-case data matrix analysis (Miles et al., 2014) conducted in Study 1. The findings for Study 2 presented here suggest that there are, in fact, distinct SLE family myths that are comprised of specific family communication behaviors and SLE narrative plotlines with which women with SLE identify. Specifically, the findings suggest that there are statistically significant distinctions between a harmonious SLE family myth and both the abandoned and battle SLE family myth. Importantly, this study suggests that differences in SLE family myths have implications for mental health and family satisfaction in the context of SLE. For example, women who reported having a harmonious SLE family myth had better mental health and were more satisfied with their family relationships than those with abandoned or battle myths. This is not surprising given that narratives are themselves both a way of knowing and a way of participating in the world (Bochner et al., 2000) and thus facilitate agency (Sharf & Vanderford, 2003) and coping (Koenig Kellas & Kranstuber Horstman, 2015) through difficult experiences such as illness. Thus, as families experience and make sense of the illness *together* (Kleinmann, 1988) in the harmonious family myth, they are able to relate and cope together. This is in contrast with battle and abandoned myths in which family coping was stunted by conflicting perspectives on SLE or no communication about SLE,

respectively. Previous research on family communication has established that disease-related conflicts and angry responses are associated with poorer health outcomes in chronic illness (Rosland et al., 2012). The results of Study 2 show that families communicate and make sense of SLE together help to provide a healthier experience for their loved ones managing SLE. Again, future research should focus on testing the construct validity of this variable through confirmatory factor analysis.

Communicated Narrative Sense-Making and Health and Well-Being in SLE

In line with previous research exploring the links between narrative sense-making and health and well-being (e.g., Koenig Kellas et al., 2010), this study supports a strong connection between narrative sense-making, health and well-being in SLE. Specifically, these findings indicate that narrative sense-making (i.e. SLE narrative plotlines and SLE family myths) is tied with improved physical and mental health and family satisfaction. Further, findings from this study support previous research that indicates that family communication behaviors (e.g., openness, confirmation in the form of communicated perspective taking) are linked to better health and well-being in chronic illness (Rosland et al., 2012). Thus, in what follows, I discuss the significance of SLE narrative plotlines, family communication behaviors, and SLE family myths on physical and mental health, family satisfaction, and self-management behavior in turn.

Implications for Physical and Mental Health

SLE is a serious autoimmune disease from which millions of Americans, primarily women, suffer that can be both life-limiting and life-threatening (Aberer, 2010; Wallace, 2008). SLE causes sometimes unmanageable pain and fatigue and can attack

any organ in the body, often attacking multiple organs, causing irreversible organ damage. The physical implications of SLE can be life-changing for those who suffer from it as well as for their families (Wallace, 2008). Thus, it is important to understand what types of narrative sense-making and family communication are associated with better physical health in SLE. In the current study, the chaotic narrative plotline was related to physical health, suggesting that the more chaotic the narrative plotline, the less physically healthy the person.

Further, mental health and well-being is essential to achieving the best possible health outcomes in illness. For example, those struggling with depression in illness are less likely to comply with medical directives, and, when adherence rates improve, so do health outcomes (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). SLE itself and some of the medications used to treat it can induce clinical chemical depression, complicating an individual's ability to cope with the physical restrictions and complications of the disease (Wallace, 2008). Further, families dealing with disability and illness are often subject to socioeconomic hardships as a result of their illness struggle. These difficulties can contribute to increased mental health problems such as depression and/or anxiety (Canary, 2008). Thus, depression is cited as the most common coping problem in lupus (Wallace, 2008). The findings of the current study suggest that the chaotic narrative plotline is related to poorer mental health and open communication about SLE is associated with better mental health. This suggests that the more chaotic the narrative plotline, the less mentally healthy the person. It further suggests that those whose family are open about SLE are mentally healthier than their counterparts whose families avoid discussions about SLE.

Social behaviors have distinct implications for health outcomes (Shapiro, 2002), and family communication provides coping resources and social support so important to positive health outcomes in illness (Pecchioni & Keeley, 2011). One fundamental method through which families provide these coping resources is through story-telling and narrative (Koenig Kellas, 2010). Though previous research has linked narrative sense-making to better mental health outcomes (e.g., McAdams et al., 2001) and indirectly to physical health outcomes in that story-telling behaviors were found to decrease stress (Koenig Kellas et al., 2010), the findings of this study suggest that chaotic narrative plotlines (i.e. contaminated restitution and ambivalent chaos) predict *both* poorer physical and mental health for women with SLE, suggesting that narrative sense-making is a critical factor in overall well-being in SLE. The connection between narrative sense-making and physical health in SLE is an important finding in that, while narrative sense-making has been linked to mental health and well-being (e.g., McAdams et al., 2001) and marital stress (Koenig Kellas et al., 2010), it has yet to be clearly linked to physical health. Thus, these findings suggest that narrative sense-making is linked to physical well-being in chronic illness, presenting an important research direction for narrative and health communication researchers.

Though these findings indicate a strong negative relationship between overall (physical and mental) health and the chaotic narrative plotline, such that those with chaotic narrative plotlines have poorer mental and physical health than their counterparts, these findings do not tell us whether the chaotic narrative plotline leads to poorer physical and mental health or whether poorer physical and mental health yields a chaotic narrative plotline. Thus, it's possible that people who frame their narratives negatively will also

experience decreases in mental and physical health, or, it may be that those who are less healthy will develop a more chaotic narrative plotline. It may be that these two processes are co-dependent, each facilitating the other. No matter the direction of the relationship, Frank (1995, 2013) suggests that chaotic narrative plotlines inhibit sense-making processes in illness. Thus, these findings further support the connection of SLE narrative plotlines and physical and mental health and well-being in illness and suggest a need to further tease out the nature of these connections.

Whereas the chaotic narrative plotline was associated with poorer physical and mental health, the harmonious SLE family myth was associated with better mental health in SLE. In other words, when one takes a gestalt look at narrative sense-making that includes the interplay of individual narrative plotlines and family communication, there exists another connection between narrative sense-making and mental health. Specifically, the harmonious SLE family myth is associated with better mental health in SLE. Additionally, and in line with previous research highlighting the importance of openness in families about illness (e.g., Caughlin et al., 2003; Rosland et al., 2012), these findings indicate that those whose families were open about SLE had better mental health than those whose families avoided discussions about SLE. Overall, these findings suggest that family communication and narrative plotlines work in tandem as women make sense of SLE in ways that have implications for their mental health.

Taken together, then, these findings support the importance of narrative sense-making for physical and mental health in SLE. Further, they suggest that family communication is, in fact, central to narrative sense-making and that family communication and narrative sense-making work together to shape the well-being for

women with SLE. Thus, these findings suggest that interventions aimed at promoting positive narrative sense-making and family communication in SLE may yield better health outcomes in this chronic illness.

Implications for Family Satisfaction

Narrative sense-making has been consistently linked to higher levels of family satisfaction (Koenig Kellas & Kranstuber Horstman, 2015). Given this, I examined the impact of narrative sense-making in SLE on family satisfaction. Findings suggest that perceptions of the family in relation to the illness (i.e. SLE family myths) were associated with family satisfaction, though specific narrative plotlines were not associated with family satisfaction. Specifically, women who reported a harmonious SLE family myth were more satisfied with their families than those that reported the battle or abandoned family myth, though there were no differences found between any of the individual SLE narrative plotlines and family satisfaction. Thus, though specific narrative plotlines by themselves were not related to family satisfaction, when narrative plotlines and family communication are taken together for a more gestalt look, narrative sense-making is related to family satisfaction.

Further, these findings suggest that women whose families engage in communicated perspective-taking behaviors about SLE were more satisfied in with their family relationships than women whose families do not engage in communicated perspective-taking behaviors. Given that perspective-taking is related to family cohesion when families tell stories of difficulty together (Trees & Koenig Kellas, 2009), it makes sense that women whose families engage in communicated perspective-taking in the context of SLE are more satisfied with their families. Further, these findings support the

findings that emerged in Study 1 indicating the significance of family confirmation of SLE and its implications for women experiencing SLE.

The results of this study point to the centrality of communication in narrative sense-making in SLE. Similar to the relationship between the narrative sense-making and physical and mental health, these findings do not explicate the direction of this relationship. In other words, it is not clear whether family satisfaction leads to a harmonious SLE family myth or whether an SLE family myth leads to increased family satisfaction. Thus, given the importance of a harmonious SLE family myth to mental health in SLE, it will be important for future research to examine the nature of this relationship.

Implications for Self-Management Behavior

Given the importance of self-management behavior in managing chronic illness, the increasing recognition of the importance of social behaviors on health and well-being in illness (Shapiro, 2002), and the fact that those with SLE report strained family relationships (Roper Public Affairs, 2011), there is an increasing need to understand the ways in which social behaviors in illness impact self-management behaviors in illnesses like SLE (Rosland et al., 2012). Given the relationship between narrative sense-making and family satisfaction found in both this study and in extant literature (Koenig Kellas & Kranstuber Horstman, 2015) and the importance of family support in self-management behavior (Rosland et al., 2012), I explored the impact of communicated narrative sense-making and family communication on self-management in SLE. The findings of this study, however, did not support these connections.

There were no distinctions among the SLE narrative plotline that guided these women's sense-making in SLE and their self-management behavior as measured in this study. Thus, women were no more or less likely to comply with medical recommendations, communicate with their physicians about SLE and its impact on their lives, or change their daily routines to accommodate SLE management (e.g., wear sunscreen regularly) based on the SLE narrative plotline that guided their sense-making about the disease.

Similarly, these results indicate no distinction between women with a harmonious, abandoned, or battle SLE family myth and their self-management behavior. Further, the findings of this study do not support the relationship between family communication behaviors and self-management behaviors in SLE. These findings run contrary to literature emphasizing the importance of family support in promoting self-management behavior in illness (Rosland et al., 2012). This may be because this study limited its focus on family communication to openness and confirmation, whereas emotional and practical family support have been linked to improving self-management behavior in illness. Specifically, individuals with families who adapt their daily routines and patterns to help manage the illness (e.g., the family of a diabetic adjusting their diet) tend to have better self-management behavior. Further, though attentiveness to the illness struggle was one element of family communication associated with improved self-management behavior, so too was a family's cohesiveness and their focus on promoting self-reliance and personal achievement (Rosland et al., 2011). Thus, it is possible that this study's focus on open and confirming family communication was too narrow to pick up distinctions in

self-management behavior. It may also indicate a need to more carefully scrutinize the self-management scale developed for this study.

Overall Implications

The process of creating and testing out population specific variables is a complex but important endeavor in conducting research focused on understanding the experience of chronic illness. Given that the experience of chronic illness is often understood and studied from one unifying view of illness (Leventhal et al., 1999) despite the idiosyncratic nature of the experience of chronic illness in general (Frank, 1995, 2013) and SLE in particular (Mendleson, 2006; Wallace, 2008), SLE narrative plotlines and SLE family myths represent an exciting opportunity for researchers to examine the particularities of chronic illness. In addition to providing a more nuanced understanding of how women with SLE experience the disease in their families, these more nuanced variables enable researchers to respond to Koenig Kellas' (2005) call to centralize communication in narrative sense-making research. Specifically, the current study enables the measurement of narrative sense-making as interdependent with family communication by using the concept of a family myth to conceptualize communicated narrative sense-making in difficult contexts (Koenig Kellas & Kranstuber Horstman, 2015). This approach may be used in future research on SLE or in other health contexts.

Ultimately, the combination of Frank's (1995, 2013) narrative types and McAdams' (1993) narrative tone into SLE narrative plotlines is a productive conceptualization of narrative sense-making in SLE that provides a more nuanced understanding than either could offer in and of themselves. In moving from a small qualitative sample aimed at understanding unique experiences to a larger quantitative

sample aimed at achieving generalizability, McAdams' (1993) narrative tone productively adds nuance to Frank's (1995, 2013)'s life-as-normal narrative plotline in the larger population of women with SLE (i.e. contaminated life-as-normal and ambivalent life-as-normal narrative plot lines).

As a variable that is comprised of narrative plotlines and family communication behaviors, these SLE family myths reflect both the central role that family plays in the process of sense-making (Pecchioni & Keeley, 2011) and the inherently communicative nature of narrative sense-making (Koenig Kellas & Kranstuber Horstman, 2015). Thus, SLE family myths provide another important opportunity for both family communication researchers and narrative researchers, particularly those interested in studying communication as central to narrative sense-making (i.e. Koenig Kellas & Kranstuber Horstman, 2015), to study family communication as central to narrative sense-making in illness. For example, SLE family myths represent a gestalt look at communicated narrative sense-making in that they encompass the interplay between SLE narrative plotlines and family communication behaviors. This provides researchers with the opportunity to study narrative sense-making as an inherently communicative phenomenon.

Overall, the integration of the themes that emerged in Study 1 into distinct SLE narrative plotlines and SLE family myths that guide sense-making in SLE provides an exciting opportunity for narrative scholars to advance our understanding of patterned narrative sense-making and its impact on overall well-being. This is particularly exciting for narrative health communication scholars because it not only provides a mechanism by which narrative sense-making in illness can be concretely linked to desirable outcomes in

managing illness, it also provides an opportunity to understand what communicative behaviors are linked to particular narrative sense-making structures. Thus, given the significance of family communication behaviors in sense-making processes (Pecchioni & Keeley, 2011) and overall health and well-being (Rosland et al., 2012), narrative researchers are positioned to explore more specifically whether and how family communication behaviors promote specific narrative sense-making structures that are more productive in managing illness. This opens up an opportunity to study the communicative nature of narrative sense-making in more depth.

Limitations

Sample

Given that as many as 90% of SLE patients are women, the focus of this study was on adult women with SLE. Thus, it excludes the 10% of patients that are men, and all pediatric cases of SLE. Given that SLE tends to be more severe in male patients (Wallace, 2008), this study does not address a small but important segment of the population of SLE patients. Given this, the distinct positioning and experience of men in the family structure (Buzzanel, D'Enbeau, & Duckworth, 2011), and the importance of family communication in sense-making about SLE, future research should be designed to understand the unique experiences of men with SLE and how they narratively make sense of their disease in family communication.

Despite the prevalence of SLE in minority populations, to include African American, Asian, and Hispanic populations (Wallace, 2008), the sample for this study consisted primarily of white women, with 117 (69%) of the participants reporting

white/Caucasian for their ethnicity. In contrast, just 20 (11.9%) reported African American, 10 (6%) reported Hispanic, and 9 (5.4%) reported Asian ethnicities. There are a number of potential explanations for the disproportionate number of white participants in this survey. First, this survey was only offered in English and thus could only be completed by English-speaking participants. Second, the survey was administered solely online and thus required that participants have access to internet access. It is possible that this limitation inhibited a segment of this population from accessing and completing the survey, thereby potentially skewing the representation of different ethnic groups in the final sample. Finally, a significant component of my recruitment strategy was working with online SLE support groups and organizations. Most of the support I received from SLE organizations was provided online (i.e., my recruitment script was posted on group Facebook pages and/or websites, or forwarded in an electronic newsletter or email). Future research should strive to include non-English speakers and those without internet access, perhaps by partnering with physicians to have a survey completed in the physician's office during regular appointment times.

Self-Management Behavior Measure

Though the self-management behavior scale developed for this study demonstrated good reliability (general compliance $\alpha=.73$, physician communication $\alpha=.80$), the items for the measure did not load solidly on two factors. Thus, given the importance of studying the implications of social processes on self-management behavior in chronic illness (Rosland et al., 2012), this scale should be further evaluated and developed to ensure it is representing good self-management behavior in the context of SLE. For example, it would be useful to build from these preliminary findings and follow

more rigorous scale development procedures that include consulting an expert panel of patients and rheumatologists (the physicians primarily responsible for managing SLE) as well as ensuring the construct validity of the measurement itself (Clark & Watson, 1995).

Co-Morbidity

The survey for this study did not include a question about co-morbidity, preventing an analysis of the differences in scores for those with other illnesses. Given the prevalence of co-morbidity in chronic illness in general (Leventhal et al., 1999) and in SLE in particular (Aberer, 2010; Wallace, 2008), this represents an important limitation that should be addressed in future research. Thus, though these findings are important in understanding SLE in general, they should be interpreted with caution.

Different Cell Sizes for SLE Family Myths

Another potential limitation of this study is the unequal sample sizes in each condition of the MANOVA that I ran to answer RQ5. Though the Box's M was non-significant ($p=.22$), indicating that the sample size in each cell was adequate, the Levene's test for homogeneity was significant for physical health ($p=.07$), suggesting that the amount of variance was not equally represented in this condition. This points to the need to interpret the non-significant findings for the impact of SLE family myths on physical health with caution.

Summary

In summary, these findings suggest the importance of family communication and narrative sense-making in managing SLE. Further, they suggest the importance of understanding how family communication and narrative sense-making intersect as

women make sense of SLE. Ultimately, this research both contributes to the theoretical conceptualization of communicated narrative sense-making and supports the value of developing and implementing narrative interventions aimed at improving health and well-being in SLE.

CHAPTER 10

OVERALL DISCUSSION

Mixed methods projects are designed to harness the strengths of qualitative and quantitative research by collecting and analyzing both types of data and integrating them to attain a more comprehensive understanding of a research problem (Creswell, 2015). As an exploratory sequential design, this particular research project was aimed at creating a more nuanced representation of women's sense-making in SLE by integrating findings from Study 1 into population specific variables for use in the design of Study 2 (Creswell, Klassen, Plano Clark, 2011). These variables reflected women's sense-making in SLE, both in terms of the plotlines guiding their sense-making (i.e. SLE narrative plotlines variable) and in terms of how family communication and narrative plotlines work together in the sense-making process. Further, Study 2 was designed to examine the links between this more nuanced representation of women's SLE experience and measures of health and well-being. Thus, in addition to facilitating a rigorous process geared at creating two population specific variables that provide a more nuanced understanding of SLE, this mixed methods dissertation makes a number of contributions to the existing family communication literature, narrative sense-making literature, as well as the mixed methodological literature. I'll detail each contribution in turn.

Contributions to Family Communication Literature

This research project both confirms the centrality of family communication to the illness experience (Pecchioni et al., 2015) and sense-making processes in illness in particular (Pecchioni & Keeley, 2011) and extends our understanding of how family communication and narrative sense-making work together in coping with SLE.

Specifically, previous research establishes that family communication shapes the illness experience in that it socializes individuals to adopt specific attitudes about health and illness (Pecchioni et al., 2015), provides social support and coping resources (Pecchioni et al., 2015; Rosland et al., 2012), is central to sense-making in illness (Koenig Kellas & Kranstuber Horstman, 2015), and shapes self-management behavior in chronic illness (Rosland et al., 2012).

The current findings further confirm this research by demonstrating that openness about SLE in the family was associated with better mental health and that communicated perspective-taking relevant to the SLE experience was associated with increased family satisfaction. In other words, the ability to talk about SLE within the family and to have others communicate their understanding of the person diagnosed with SLE are significant to individual and relational well-being. Because illness changes social relationships (Beach, 2002) in that it can increase anxiety, uncertainty and stress in the family (Rolland, 1994; Miller-Day, 2011), thus creating barriers to open communication about illness in the family (Caughlin et al., 2011), the findings of the current study indicate a need to translate to families the importance of these communicative practices within the context of SLE.

Further, given that emotional closeness is associated with increased openness in the family (Hay et al., 2009), the findings presented here provide insight into how families managing SLE can achieve emotional closeness and thus improve openness about SLE that will yield improved mental health for those managing the disease. Specifically, openness was associated with better mental health and communicated perspective taking was associated with increased family satisfaction in women with SLE.

Thus, future research should explore the degree to which perspective-taking behavior increases emotional closeness in families managing SLE.

Given that women whose families avoided discussions about SLE fared worse mentally than those whose families discussed the disease openly, future research should explore whether disease-specific avoidance predicts negative plotlines and/or whether negative plotlines predict disease-specific avoidance. Further women whose families failed to acknowledge and confirm (i.e. engage in communicated perspective taking) their experience with SLE were less satisfied in their families, thus, future research should explore whether communicated perspective-taking behaviors predict family satisfaction or if family satisfaction predicts communicated perspective-taking behaviors.

Contributions to Narrative Sense-Making Literature

This research project contributes to the narrative sense-making literature in a number of ways. First, it confirms the importance of narrative sense-making on health and well-being (Koenig Kellas & Kranstuber Horstman, 2015). Second, it confirms the centrality of family communication on narrative sense-making in illness (Pecchioni & Keeley, 2011) and provides evidence for the interdependent nature of family communication and narrative sense-making in illness. Finally, it makes significant theoretical contributions to this body of literature.

Narrative sense-making and health and well-being. First, in line with previous research that has linked narrative sense-making to health and well-being (Koenig Kellas & Kranstuber Horstman, 2015), this research project confirms the importance of narrative sense-making to health and well-being in SLE. For example, narrative coherence is

associated with health and well-being (Koenig Kellas et al., 2010) and contaminated narratives are associated with poorer mental health (McAdams et al., 2001). This study confirms these findings in that the chaotic narrative plotline (a narrative plotline defined by a lack of narrative coherence and with no expectation for positive outcomes) was associated with poorer physical and mental health in SLE. The more research that quantitatively tests and confirms the significant links between narrative framing and individual well-being, the more implications and guidance there are for researchers and practitioners wishing to create and implement effective, psychosocial interventions to improve the well-being and care of ill people and their families.

Narrative sense-making and family communication. Pecchioni & Keeley (2011) claim that families are central sites for sense-making and Koenig Kellas (2005) claims that communication is central to narrative sense-making. The findings of this study suggest that family communication and narrative sense-making can be parsimoniously and heuristically operationalized as working in tandem via SLE family myths. Women with a harmonious SLE family myth were more satisfied with their families, and had were more mentally healthy than their counterparts who were guided by either an abandoned or battle SLE family myth. Recall that SLE family myths represent the synthesis of narrative sense-making and family communication. Thus, in addition to confirming the connection between narrative sense-making and health and well-being, this study also suggests that family communication and narrative sense-making interact in distinct ways to shape the way chronically ill individuals make sense of their illness. These findings are significant for a number of reasons. First, illness is itself a loss of control (Charmaz, 2000) and requires ongoing sense-making (Frank, 1995, 2013). Like

communication, narratives are a means through which individuals who are sick can claim agency in their illness experience (Sharf & Vanderford, 2003). Thus, the recognition that narratives and communication work in tandem to shape sense-making in illness and that this sense-making has distinct implications for health and well-being suggests that an opportunity exists for researchers to develop meaningful interventions that can improve the individual and family experience of SLE.

Second, in line with Miller-Day's (2011) call for researching the interconnections of family and health communication and Koenig Kellas' (2005) call for studying communication as central to narrative, the existence of SLE family myths comprised of distinct SLE narrative plotlines and family communication behaviors provides both evidence for and a means through which to study the interconnectivity of family communication, narrative sense-making, and health. In essence, the SLE family myth represents a unique opportunity for narrative scholars, family communication scholars, and health communication scholars to study the way the intersections of their disciplines play out in the context of a specific disease. Thus, this new variable represents an important opportunity to gain a more in depth, rich understanding of an experience from an interdisciplinary perspective.

Theoretical contributions. The study of chronic illness is a difficult endeavor to undertake given the need to respect and honor the idiosyncratic nature of the illness experience itself (Leventhal et al., 1999) and the need to understand the implications of communicative patterns inherent in communicating about difficulty like illness. Understanding illness from both of these vantage points will enable us to both understand the nuances of illness and identify specific patterns that can be connected with health and

well-being. Thus, communicative patterns specific to particular illness experiences can be promoted in interventions aimed at improving health and well-being in illness (Koenig Kellas & Kranstuber Horstman, 2015).

The use of CNSM as a conceptual model and the mixed methods research design of this project provided the space to explore and honor the idiosyncratic nature of the SLE experience (Mendleson, 2006) and provided the mechanism by which patterns could be identified in the process of making sense of SLE. Specifically, Study 1 identified six narrative plotlines that guided women's sense-making in SLE (i.e. ambivalent life-as-normal, ambivalent chaos, contaminated life-as-normal, ambivalent quest, contaminated restitution, redemptive quest). In attempting to identify patterns in the experience of women with SLE that could be connected to measures of health and well-being, Study 2 collapsed these six narrative plotlines into four (ambivalent life-as-normal, contaminated life-as-normal, quest, and chaotic). This research project, then, was able to tease out and highlight the slight differences in the way SLE is experienced (e.g., ambivalent versus redemptive quest, contaminated restitution versus ambivalent chaos) and understood in family contexts; it was also able to discern patterns that could connect sense-making processes with measures of health and well-being.

Thus, this study confirms the heuristic value of CNSM as a conceptual model that has both the theoretical sophistication and paradigmatic flexibility to facilitate the ability of researchers to study complex experiences like SLE and other chronic illnesses comprehensively in one research project. Given this, this research advances our understanding theoretically in that it validates the utility of CNSM (Koenig Kellas & Kranstuber Horstman, 2015) as a theory capable of guiding both the qualitative and

quantitative strand of a mixed methods project and understanding both the idiosyncratic and patterned nature of narrative sense-making.

Illness Narratives and Narrative Tone. This research project makes another important theoretical contribution to the narrative sense-making literature in that it empirically confirms Frank's narrative types as sense-making frameworks that resonate for women living with SLE. Further, it confirms that McAdams' (1993) concept of narrative tone is an important distinction in sense-making through illness. In other words, this research suggests that narrative sense-making in illness is guided by plotlines that can be understood in terms of both illness narrative types (Frank, 1995, 2013) and narrative tone (McAdams, 1993). This finding suggests that, though illness narrative types (i.e. restitution, quest, chaos, life-as-normal, borrowed, broken) provide important insight into sense-making in illness, they are not the whole picture. As a person makes sense of illness, they are (re)constructing themselves in the face of that illness (Charmaz, 2000). Though illness narrative types provide a basic plotline for understanding illness (Frank, 1995, 2013), narrative tone reflects the emotion or attitude of that individual's narrative and is itself central to narrative identity (re)construction (McAdams, 1993). Thus, these findings address the interconnectivity of narrative sense-making and identity (re)construction as simultaneous coping processes in the illness experience.

Contributions to Mixed Methods Literature

This study makes contributions to the mixed methods literature both theoretically and methodologically. Rigorous mixed methods research projects should be positioned within a theoretical framework or conceptual model that guides the qualitative and quantitative exploration (Creswell, 2015). Unlike emancipatory theories, social scientific

theories that guide mixed methodological projects are often positioned at the beginning of a project and are not commonly threaded throughout it (Creswell & Plano Clark, 2011).

This study, however, takes a social scientific theoretical approach (i.e. CNSM) and uses it to not only frame the project in the beginning, it threads the model throughout the project so that it informs the qualitative and quantitative strand of the project as well as the overall interpretation of the findings.

Though CNSM is a theory situated within the post-positivist paradigm (Koenig Kellas & Kranstuber Horstman, 2015), I argue that it has the potential to straddle social constructivist and post-positivist orientations in that it recognizes the multiple meanings inherent in narrative construction (social constructivist), creating space for the qualitative exploration of particular illness narratives even as it facilitates the identification and correlation of narratives and patterned communication (post-positivist). Thus, both strands of this mixed methods research project are guided by this theory, not only providing the necessary space to explore multiple participant meanings and facilitates an examination of the relationships between these meanings and health and well-being, but also providing for a consistent, over-arching theoretical orientation throughout the conceptualization and execution of this research project. Given the importance of theory to conducting rigorous mixed methods research (Creswell, 2015), the ability to work within a consistent theoretical framework that provides the necessary paradigmatic flexibility central to conducting mixed methods research bolsters the rigor of this particular project.

In addition to the importance of theory in mixed methods research, integration between methodological strands is also essential. Despite the centrality of integration to

mixed methods research, many research projects that claim a mixed methods orientation fail to explicate the process of integration. In an exploratory sequential design, integration occurs by building from the analysis of the qualitative data in approaching the quantitative strand (Creswell, 2015). This project engaged the integration phase between Study 1 and Study 2 in several ways. First, I engaged in data transformation (Fetters et al., 2013), a process by which qualitative themes are transformed into quantitative variables. Specifically, in conducting the cross-case data matrix analysis, the themes that emerged in the thematic analysis in Study 1 were grouped into specific SLE family myths, a categorical variable that is both specific to this under-studied population and advances our ability to study communication as central to narrative sense-making in illness. Using participant language, narrative descriptions were developed to represent each of the three categories for this variable for use in the quantitative survey.

In addition, I also created a quantitative measure of narrative plotlines that was derived directly from the findings in Study 1. Specifically, the themes that emerged in each SLE narrative plotline were used to create items for the scale that measured the SLE narrative plotlines that were most prominent for the participants in Study 2. In conducting the Principle Components Analysis on the emergent SLE narrative plotlines, the redemptive quest and ambivalent quest were collapsed to form a single quest SLE narrative plotline and the ambivalent chaos and contaminated restitution plotlines were collapsed into the chaotic narrative plotline.

Interestingly, in conducting the cross-case data matrix analysis from Study 1, the harmonious SLE family myth was comprised of all those participants classified as having the ambivalent quest *and* redemptive quest narrative plotline as well as one participant categorized as having the ambivalent life as normal narrative plotline. Further, the battle SLE Family myth consisted primarily of participants with the contaminated life-as-normal narrative plotline, one with an ambivalent life-as-normal plotline and one with a contaminated restitution narrative plotline, both of whom reported avoidant and disconfirming communication. Finally, the abandoned SLE family myth consisted primarily of ambivalent chaos narrative plotlines, with the exception of one who reported a contaminated restitution plotline and who also reported avoidant and disconfirming family communication. Taken together, the combined findings from Study 1 and Study 2 indicate that each SLE family myth is comprised of a distinct combination of SLE narrative plotlines and specific family communication behaviors.

Thus, from a methodological standpoint, this study extends our understanding of data transformation and creates two new, distinct variables specific to women with SLE. Specifically, it advances our understanding methodologically by introducing the cross case data matrix analysis as method of data transformation to formulate the SLE family myths variable. Further, this move to create two new population-specific variables demonstrates the value of an exploratory sequential design in identifying and creating a population specific variable to better represent under-studied populations in subsequent research projects (Fetters et al., 2013). SLE family myths, as a variable specific to women with SLE, can be used to conduct research that represents this understudied specific population.

In sum, though many mixed methods research projects fail to explicate the way qualitative and quantitative data is integrated, integration is key to conducting a rigorous mixed methods research project (Creswell, 2015). It is the integration of qualitative and quantitative data that provides the researcher with the capability of gaining a more comprehensive, in depth understanding of a particular phenomenon. In this research project, the rigorous integration of qualitative and quantitative data enabled me to understand and honor the idiosyncratic nature of SLE and make statistically significant connections between emergent themes and measures of health and well-being, providing families and medical practitioners living and working within the context of SLE with concrete outcomes and strategies for improving the quality of life for women with SLE.

Implications for Patients, Families, and Practitioners

The findings of this study advance our knowledge pragmatically in the context of women's experience with SLE. Specifically, it identifies specific SLE narrative plotlines and family communication behaviors that guide sense-making in SLE and correlates them with measures of physical, mental, and relational health and well-being. Taken together, this study provides valuable insight not only into the experience of women with SLE in their families, but provides a foothold for those managing this illness interested in improving their overall health and well-being. The findings of this study suggest that open communication and communicated perspective-taking behaviors are positively related to individual and relational health and well-being in the context of SLE. It is clear that a redemptive narrative about SLE that is, at its core, free from the expectation of negative outcomes from the illness is associated with positive health outcomes than the alternative.

Though these findings suggest that family communication is associated with positive health outcomes in SLE, we do not know the direction of this relationship. For example, it may be that when people are healthier in the context of SLE they tend to be more open and experience more confirming behavior from their families. Conversely, it might be that when people are more open about their SLE and perceive their family communication as more confirming of their disease, they become healthier. Thus, future research should tease out the direction of this relationship so that we can examine the utility of interventions aimed at teaching family members how to communicate better in SLE.

Second, based on the findings that chaotic narrative plotlines are associated with poorer physical and mental health and that harmonious SLE family myths (comprised of ambivalent life-as-normal and quest narrative plotlines) are associated with better mental health and more family satisfaction, it appears as though women who frame their narratives as either a normal part of their life (ambivalent life-as-normal) or as an opportunity to improve others' experience in SLE (quest) also report higher levels of well-being. These findings suggest that narrative interventions in SLE could improve health and well-being. Specifically, those living and working within the context of SLE may benefit from narrative interventions aimed at helping families make sense of SLE together.

Given the clear benefit in jointly constructing a coherent narrative as families make sense of difficulty together (e.g., Trees & Koenig Kellas, 2009), such interventions may be aimed at helping families construct a joint story of SLE. Alternatively, based on the finding from this study that communicated perspective-taking is related to family

satisfaction and the connection between both emotional closeness and openness in illness (Hay et al., 2009) and openness and well-being in illness (Rosland et al., 2012), interventions may be centered on teaching family members how to take one another's perspectives in illness. Specifically, family members could be taught to bear witness to one another's stories, as in Charon's (2006) narrative medicine. This narrative interventionist approach focuses on hearing and acknowledging one another's experiences, and communicative behavior that emerged in both Study 1 and Study 2 as integral to the overall experience of SLE in the family. Finally, based on the finding that the chaotic narrative plotline is associated with poorer physical and mental health and in line with White (2007), we could consider conducting interventions aimed at re-framing the individual's SLE narrative plotline, targeting those individuals working from a chaotic narrative plotline.

Ultimately, this study provides evidence for the importance of family communication and narrative sense-making in managing SLE. It is clear that women with SLE who report that their families seek to support and understand their experience of SLE also report higher levels of physical, mental, and relational health. This may mean that family communication predicts well-being. Future research should test the directionality of this relationship. Further, it suggests the importance of a narrative plotline that is not chaotic in nature. Thus, women with SLE and their families would benefit from working together to construct a narrative that facilitates sense-making in SLE. These findings suggest that engaging in both open communication and communicated perspective-taking behaviors may support this aim, though this will need to be tested in future research.

Limitations

Though I've discussed limitations of each specific strand of this mixed methods project (i.e. Study 1 and Study 2), I now discuss limitations to this mixed methods research project as a whole. Mixed methods research projects are designed to harness the strengths of both qualitative and quantitative data in order to get a comprehensive understanding of a particular phenomenon. In fact, mixed methods researchers presuppose that the explicit integration of qualitative and quantitative data is integral to achieving this more comprehensive understanding (Creswell, 2015). Despite the importance of integration to conducting solid mixed methods research, this process is not without its limitations. Specifically, in moving from an in depth understanding of the idiosyncratic sense-making process in SLE that emerged in Study 1 to a more generalized understanding of the experience of SLE in Study 2, some of the nuance in our understanding is lost. For example, the contaminated restitution SLE narrative plotline and the redemptive quest narrative plotline that emerged as distinct SLE narrative plotlines in Study 1 were not supported as distinct experiences in the larger population in Study 2. Though each of these SLE narrative plotlines were described by two participants each in Study 1 and thus not as common as the other SLE narrative plotlines that emerged, they were identified in accordance with Owen's (1984) criteria of forcefulness. This criterion allows researchers to identify and honor those experiences that are less commonly reported but that emerge as strongly felt, important representations of experience for specific participants. Thus, the intent of Study 1 to understand and honor diverse and nuanced experiences of this population is in conflict with the intent of Study 2, to understand the typical sense-making processes in SLE. Though we do gain a more

comprehensive understanding of these experiences in looking at these data in conjunction with one another, the integration process central to mixed methods research requires that those experiences that are less common yet legitimate nonetheless be collapsed into a less nuanced understanding of the experience.

A second limitation of integration in this mixed methods research design is the use of participant language from Study 1 in developing the items for the SLE narrative plotlines in Study 2. Though the intent of this move was to ensure accurate representation of experience as identified in Study 1 in the design of Study 2 (Creswell & Plano Clark, 2011), it is possible that, in some cases, the use of participant language for specific items did not resonate with other participants who share the same experiences, thus inhibiting the ability of the item to adequately represent the experience for all participants. For example, “I’ve accepted that that I will just have to roll with what SLE throws my way” was an item created using specific language of one of the participants in Study 1. This item did not load well in the initial principal components analysis, suggesting possible weakness in the item. Similarly, “I keep thinking that I might be able to go back to work and/or to live my life the way I did before I got SLE, though I do not see this as a realistic goal” was an item created using the specific language from a participant in Study 1, but that was ultimately removed from the analysis based on its poor loadings in the factor analysis. Thus, though the use participant language protects the integrity of integration in mixed methods designs, it may not always be the best approach to survey design. Future research should further confirm these measures and/or modifications to them through confirmatory factor analysis and test of validity. Additional future directions are discussed below.

Future Directions

This research project suggests a number of directions in which to conduct future research, both pragmatically in order to gain a better understanding of communication processes in the context of SLE and theoretically in understanding the interdependence of communication and narrative sense-making in illness. I will first discuss directions for research in understanding SLE and end with a discussion on how the findings of this research project support the utility in additional exploration of sense-making processes using CNSM.

Broaden our Understanding of Experience of SLE

First, this research project points to the significance of family communication and narrative in sense-making about SLE. It is clear that SLE, like other chronic illnesses, is a disease that requires ongoing sense-making (Charmaz, 2000). Further, it is clear that family communication processes are central to sense-making in SLE (Pecchioni & Keeley, 2000). Finally, family communication and narrative sense-making processes have implications for the overall health and well-being of women managing SLE. Given this and the prevalence of SLE in the United States, particularly in minority populations (Wallace, 2008), it is important that we understand how these processes impact all those suffering from SLE.

The sample for this study represents some diversity, but it is not representative of the minority populations that tend to be hardest hit by SLE. For example, African American women, Hispanic women, and Asian women tend to have more severe disease processes than Caucasian women (Aberer, 2010; Wallace, 2008). Further, family

communication and support looks different in different cultural contexts (Sillars, 1995). Thus, future research aimed at understanding social behaviors and their impact on SLE should be specifically aimed at understanding family communication processes in different ethnic populations. Researchers should ensure they can reach non-English speaking populations and populations that may not have ready access to the internet. In fact, I have been in conversation with both a rheumatologist at the University of Nebraska Medical Center and the National Program Director at the S.L.E. Lupus Foundation about conducting research that captures the experiences of minorities living with SLE. Both of these individuals have offered their assistance both with recruiting minority participants with SLE and working to provide access to these individuals to surveys. For example, the UNMC physician suggested putting the survey on an iPad that patients could complete in her office.

Similarly, though SLE patients are primarily women, 10% of SLE patients are men. Further, a man diagnosed with SLE is likely to have severe and debilitating symptoms (Wallace, 2008). Given the distinct social positioning of men in the family (Buzzanell et al., 2011), it will be important for future research to explore this sub-set of the SLE population in more detail. Based on my recruitment for both Study 1 and Study 2, there are groups that are specific to men with SLE and I do plan to conduct a study similar to this one focused on the experience of men with SLE.

In addition to the sample composition, family communication and narrative sense-making in the context of SLE should also be studied from the perspective of well family members. Though illness itself has been demonstrated to be a family experience (Kleinman, 1988; Rolland, 1995), it is rarely studied from the perspective of the well-

family members (for an exception see Branstetter, Domian, Williams, Graff, & Piamjariyakul, 2008 and Hay et al., 2009). The findings from this study suggest that SLE is complex experience to make sense of not only for those managing the disease, but also for their family members. Given the centrality of the family in sense-making (Pecchioni & Keeley, 2011), and the findings from this study that suggest the importance of family support in making sense of SLE, it will be important for future research to explore how family members make sense of SLE. Specifically, I plan to develop a study that examines the experiences of well-family members in the context of SLE. Given that research on well-family members is limited, this study will be an interview study aimed at understanding the way family members of those with SLE manage the disease as a part of their family life. Despite the importance of family on SLE, medical professionals play a significant role in making sense of illness.

Women with SLE see physicians (often multiple physicians) on a regular basis as they manage their disease (Mendleson, 2006). Communication with medical providers is central to determining the way patients view themselves following an illness experience (Leventhal et al., 1999), and likely influencing the way SLE patients make sense of their illness. Patient-physician communication in the medical encounter shapes and is shaped by the patient's emerging illness narrative. For example, medical providers narrate diagnoses and these narratives are imbued with institutional language of medicine that endow diagnoses and treatment processes with meaning (Corbin, 2003) by situating them within the larger biomedical narrative (Harter et al., 2010). For example, when a person goes into a physician's office complaining of back pain and the physician provides a diagnosis of multiple myeloma, the ill individual learns a great deal about that particular

condition as the physician explains and interprets his personal narrative of illness biomedical language. Thus, the emergent illness narrative is situated squarely within the medical institution. Alternatively, the absence of a diagnosis in the medical context is also imbued with meaning and significantly impacts the patient's illness narrative in that it is held in abeyance until the symptoms that are experienced receive some sort of medical legitimization (Mendleson, 2009).

Further, it is clear that open and honest communication with medical providers can help patients manage their developing sense of self in the context of illness (Villagran & Sparks, 2010) as they co-construct their illness narrative. Ultimately, communication with medical providers has the potential to provide narrative resources, or knowledge, (Manoogian et al., 2013), that can help patients make sense of and manage the identity threat the illness poses (Charmaz, 1999). Alternatively, communication with medical providers can withhold narrative resources that exacerbate it, is in the case of a delayed or absent diagnosis (Weingarten & Weingarten Worthen, 1997). Given this, it is important that future research explore the way communication with medical providers shape sense-making in SLE. I have collected data to help address this issue, as the interview for Study 1 included questions about medical communication in SLE. I plan to analyze those data to see what emerges as significant to these women's experiences and understanding of SLE.

Ideal Openness

Though the findings of this study indicate that openness about SLE in families is associated with better mental health, it is possible that some women with SLE do not view openness as positive or conducive to their coping and management of SLE.

Openness is complex in illness (Caughlin et al., 2011), and privacy management is itself a significant issue in illness contexts, both within and outside the family unit (Miller-Day, 2011). Thus, future research should explore what, if any, correlations exist between what women with SLE indicate is their ideal amount of openness about SLE in the family and physical and mental health in SLE. As a part of the data collection for this dissertation, participants were asked to rate what they perceived to be the ideal amount of openness in the context of SLE. Thus, I plan to analyze these data to better understand the complexities of openness/avoidance in the context of SLE.

Translational: Interventions

Finally, the findings presented here suggest the potential value of developing and testing family-level interventions aimed at developing communication and narrative sense-making skills in families managing an SLE diagnosis. As medical care shifts from the treatment of *acute*, or short term, to the management of *chronic*, or ongoing, illness (Allen et al., 2011) it is becoming increasingly important to support patients and their families in their ability to manage chronic illnesses outside the clinical setting (Telford et al., 2006). Narrative researchers have successfully translated narrative theory to develop narrative interventions that teach pro-health strategies (e.g. Beach, 2002; Hecht & Miller-Day, 2007). Further, White (2007) has translated narrative theory into a therapeutic practice aimed at helping individuals re-frame dis-preferred narratives in making sense of their life experiences. Given this and the findings from this study that support the importance of narrative sense-making in SLE, future research should explore the utility of narrative interventions in helping patients with SLE and their families develop productive SLE narrative frameworks that are associated with positive health outcomes.

Specifically, I plan to first develop a study that has an experimental design and thus will enable me to determine whether chaotic narrative plotlines cause poorer physical and mental health, or if poor physical and mental health cause chaotic plotlines. I also plan to test the SLE family myths to determine if a harmonious SLE family myth leads to increased family satisfaction and better mental health or if family satisfaction and mental health lead to a harmonious SLE family myth.

The next step is, if I find that chaotic SLE narrative plotlines do, in fact, contribute to relatively poorer physical and mental health in women with SLE, I will develop interventions aimed at re-framing narrative plotlines. These interventions will be informed by White's (2007) emphasis on narrative re-framing in his approach to narrative therapy and Charon's (2006) focus on bearing witness to the story of women with SLE in her approach to narrative medicine.

Theoretical: CNSM

Finally, this study further confirms the value of communicated narrative sense-making as theory for understanding the inherent communicative nature of narrative sense-making and its links to well-being. Specifically, the SLE family myth variable comprised of both SLE narrative plotlines and specific family communication behaviors (i.e. open-avoidant and confirming-disconfirming) suggests that narrative sense-making is intertwined with family communication processes. Given the strong evidence pointing to the centrality of family communication in narrative sense-making (Pecchioni & Keeley, 2011) and the interdependence of family and health communication (Miller-Day, 2011), it remains important for family and health communication as well as narrative researchers to explore the ways in which their disciplines intersect in the illness

experience. Thus, future research should continue to explore the interdependence of family communication, health communication, and narrative sense-making as directed by CNSM. One way to do this is to validate the variables that were created in this study by conducting a confirmatory factor analysis that tests the reliability and validity of the SLE family myth variable. This would position this variable as a gestalt conceptualization of narrative sense-making and family communication that can be used reliably to understand the way family communication and narrative sense-making work together in the context of SLE. Once this step is taken, researchers can use this variable to understand the interplay of family communication and narrative sense-making in the context of other illnesses.

Conclusion

Ultimately, systemic lupus erythematosus is a serious, life-altering and sometimes life-threatening disease that affects more than 1 million people in the United States, primarily women (Wallace, 2008) and is characterized by strained family relationships (Roper Public Affairs, 2011). Given the importance of narrative sense-making (Koenig Kellas & Kranstuber Horstman, 2015) and family communication on health and well-being in illness (Pecchioni et al., 2015), this research project sought to explore the implications of narrative sense-making and family communication on health and well-being in SLE. While managing and honoring the idiosyncratic nature of the SLE experience (Aberer, 2010; Wallace, 2008), this project ultimately found that those women with SLE who had chaotic narrative plotlines were less physically and mentally healthy than their counterparts. Further, those whose families were open about SLE were mentally healthier than those who experienced avoidant communication, and those whose

families engaged in communicated perspective-taking were more satisfied with their families than those who did not engage in this confirming behavior. Thus, these findings can benefit those living and working within the context of SLE.

In addition to linking narrative sense-making to health and well-being in SLE, this research project contributed both to our methodological and to our theoretical understanding. First, it provides insight into the interplay of communication and narrative sense-making in illness in that it provides the foundation for establishing two new variables specific to sense-making in SLE, one that explicitly integrates family communication and narrative plotlines. Further, this project contributes to mixed methodological literature in that it both demonstrates the use of a social scientific theory (CNSM) that encompasses the totality of the mixed methods project, and also details the use of cross-case data matrix analysis to integrate findings from the qualitative strand of an exploratory sequential design into the quantitative strand. Thus, in addition to benefiting those living and working within the context of SLE, the findings from this research project can benefit other researchers interested in studying the social aspect of SLE.

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Appendix A

Study 1 Interview Protocol

I am from the Communication Studies Department at the University of Nebraska-Lincoln and am your interviewer today. We are working on a research project that focuses on communication in SLE lupus. To participate in this interview, you must be at least 19 years of age and you must have been diagnosed with SLE lupus by a medical physician at least one year ago, but it can certainly have been longer than a year ago. Does this describe you?

Let me describe what we are going to do today:

First, I want to take you through the informed consent form and procedures for the study so that you clearly understand your rights.

Second, I am going to ask you some demographic questions.

Third, I will ask you to tell me the story of your illness.

Fourth, I will ask you some questions about your communication about your illness with members of your family and with your medical providers.

My hope is to understand your personal experience with SLE lupus as fully as I can. I want you to provide as much detail as you are comfortable doing. If you can provide examples of what you are describing, that helps me understand your experience better. I would like you to include everything that you feel is important to include as we talk about these things. Does that make sense? Do you have any questions for me before we begin?

Demographic Questions

First, I have a few questions about you:

- A) Age
- B) Ethnicity
- C) Highest level of education
- D) Your current profession
- E) Marital status
- F) Children?
- G) When were you diagnosed with SLE lupus?
- H) When did you begin noticing symptoms? (approx. date)

ILLNESS STORY

1. I'd like to know your story of illness. Can you tell me your illness story?
 - a. Start from whenever you think your illness story starts
 - b. Include whatever is important to you about your story

FAMILY COMMUNICATION

2. How do you talk about your illness in your family?
 - i. What do you talk about?

- ii. When do you talk about it?
 - iii. Who do you talk to about it?
 - iv. Who or what do you avoid talking to about it?
- 3. How does your family talk about your illness?
 - a. What do they talk about?
 - b. When do they talk about?
 - c. Who avoids talking with you about it?
- 4. How do you characterize/describe your illness to family members?
 - a. What is emphasized?
 - b. What is the tone?
 - c. Any metaphors or phrases or images that come to mind?
- 5. What are barriers to talking about your illness in your family?
- 6. What facilitates communication about your illness in your family?
- 7. How do your family members characterize/describe your illness?
 - a. What is emphasized?
 - b. What is the tone?
 - c. Any metaphors or phrases or images that come to mind?
- 8. Can you think of a particularly “good” conversation you had about your illness with someone in your family? Can you describe that?
 - a. What was good about it?
 - b. What did it do for you? For your family member?
- 9. Can you think of a particularly “bad” conversation about your illness with someone in your family? Can you describe that?
 - a. What was bad about it?
- 10. How would you describe your ideal communication in your family about your illness? What’s something to strive for in the way you communicate in your family about your illness?
- 11. If you could instruct your family on how best to talk with you about your illness, what would you say?

Appendix B
Study 2 Quantitative Survey Instrument

Demographics

Please fill out the following information:

Your age: _____

Marital Status:

_____ Married

_____ Widowed

_____ Divorced

_____ Dating

_____ Separated

Children Yes or No. Children's Ages (Open Text Box to List Ages)

Your ethnicity:

_____ White/Caucasian

_____ Asian

_____ African American

_____ Hispanic

_____ Native American

_____ Other (Open Text Box)

Highest Level of Education

_____ Grade School

_____ High School Diploma

_____ Bachelor's Degree

_____ Master's Degree

_____ Doctoral Degree

_____ Other (Open Text Box)

Currently Working? Y N If Yes, Please List Your Current Profession _____ If
No, Please List Your Previous Profession _____

When did you first begin noticing symptoms (month and year)? _____ (Open Text Box)

Approximately when were you diagnosed with SLE (month and year): _____ (Open Text Box)

Do You Have Organ Involvement Yes or No. If yes, please list organs involved

Is your disease visible to others? Yes or No.

Have you completed any other study (interview or survey) about your experiences with lupus in the last 12 months? Yes or No.

On a scale of 1-7, with 1 meaning not at all and 7 meaning always, please rate the extent to which you suffer as a result of SLE:

- 1: Not at all
- 2: Once in a while
- 3: Sometimes
- 4: Half of the time
- 5: Often
- 6: Most of the time
- 7: Always

SLE FAMILY MYTHS

Please choose which of the following descriptions **best** describes your experience with SLE in your family. In answering questions about family on this survey, please use your definition of family. In other words, family includes whomever you define as family in your life.

Harmonious SLE Family Myth: My family supports my experience with SLE. They talk openly about the illness with me and I feel comfortable discussing it when I want to discuss it. My family regularly expresses their concern for my well-being and seeks out and/or are open to learning about the disease. My family works with me to manage SLE.

Abandoned SLE Family Myth: I feel alone in managing SLE. My family members avoid talking with me about it and I don't feel as if I can initiate discussions about SLE with them. I feel that my family members don't believe that I have SLE, or, if they do, they don't believe that it is a struggle for me to manage it. My family members do not seem concerned for me as I manage this disease.

Battle SLE Family Myth: I feel tension with my family members about my SLE. I feel like my family and I are at odds with our expectations for managing this disease (e.g., a focus on recovery as opposed to a focus on disease management and/or quality of life with an illness that is not curable). I am not able to talk openly in my family about SLE because I get the feeling that they are tired of hearing about it.

Relational Plot Lines: Please rate the degree to which you agree with each of the following statements on a scale from 1-5 where 1 indicates strongly disagree and 5 indicates strongly agree.

Ambivalent Life As Normal:

I have accepted SLE is a normal part of my life.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

When I have symptoms, I do what I can to keep things normal for myself.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

When I have symptoms, I do what I can to keep things normal for my family.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I've accepted that SLE is here to stay.

- 1: Strongly Disagree
- 2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I've accepted that I will just have to roll with what SLE throws my way.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

Ambivalent Chaos:

Every day is a struggle with SLE.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

When I have symptoms it feels like they will go on forever.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I have difficulty with all aspects of my life because of SLE.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I feel like I'm always waiting and wondering what's going to happen next.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

Ambivalent Quest:

My experience with SLE has been helpful to others in my life.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I feel that my experience with SLE has helped me become who I am.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I believe that my experience with SLE has helped others manage their own experience with SLE.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I use what I have learned through my experience with SLE to help others in my daily life.

- 1: Strongly Disagree
- 2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

Contaminated Life-As-Normal:

I feel that my family members have a different idea of what normal is with SLE.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I feel like my efforts to live normally with SLE are not well understood by my family members.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I feel like my family members are tired of talking about SLE.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

I often feel like my family minimizes my symptoms.

1: Strongly Disagree

2: Somewhat Disagree

3: Neither Agree nor Disagree

4: Somewhat Agree

5: Strongly Agree

There is tension in my family about how to live with SLE.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

Contaminated Restitution:

I had to quit many of the things that I did before I was diagnosed with SLE (working, active life style).

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I feel like others see me as lazy because I can no longer do things the way I did before I got SLE.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I get frustrated with myself when I cannot do the things I did before getting SLE.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I keep thinking that I might be able to go back to work and/or to live my life the way I did before I got SLE, though I do not see this as a realistic goal.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I continue to fight for recovery from SLE despite my continued struggle with complications and flares from the disease.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

Redemptive Quest:

I see my experience with SLE as an opportunity to change the way society views SLE and chronic illness.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I see my experience with SLE as a chance to educate society about suffering in illness.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I see my experience with SLE as a chance to teach others in our society living with SLE how to live better in illness.

- 1: Strongly Disagree

- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

I have taken steps toward enacting social change because of my experience with SLE.

- 1: Strongly Disagree
- 2: Somewhat Disagree
- 3: Neither Agree nor Disagree
- 4: Somewhat Agree
- 5: Strongly Agree

RELATIONAL HEALTH AND WELL BEING

Questions About Your Relationship

(Huston, McHale, Crouter 1986)

Directions: we would like you to think about your **family relationships** over the last month. Please circle the number that most closely describes your feelings toward *your family relationships* over the past month. In answering questions about family on this survey, please use your definition of family. In other words, family includes whomever you define as family in your life.

Miserable:	1	2	3	4	5	6	7	: Enjoyable
Hopeful:	1	2	3	4	5	6	7	: Discouraging
Free:	1	2	3	4	5	6	7	: Tied Down
Empty:	1	2	3	4	5	6	7	: Full
Interesting:	1	2	3	4	5	6	7	: Boring
Rewarding:	1	2	3	4	5	6	7	: Disappointing
Doesn't give me much chance:	1	2	3	4	5	6	7	: Brings out the best in me
Lonely:	1	2	3	4	5	6	7	: Friendly
Hard:	1	2	3	4	5	6	7	: Easy
Worthwhile:	1	2	3	4	5	6	7	: Useless

All things considered, how satisfied have you been with your **family relationships** the last month (circle one)?

1	2	3	4	5	6
Completely			Neutral		Completely
Dissatisfied					Satisfied

Physical and Mental Health

(<http://www.sf-36.org/tools/SF36.shtml>).

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities.

Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- c Were limited in the kind of work or other activities ☐ ☐ ☐ ☐ ☐
- d Had difficulty performing the work or other activities (for example, it took extra effort) ☐ ☐ ☐ ☐ ☐

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- | | All
of the
time | Most
of the
time | Some
of the
time | A little
of the
time | None
of the
time |
|--|--------------------------|--------------------------|--------------------------|----------------------------|--------------------------|
| a Cut down on the amount of time you spent on work or other activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c Did work or activities less carefully than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Not at all | Slightly | Moderately | Quite a bit | Extremely |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. How much bodily pain have you had during the past 4 weeks?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| None | Very mild | Mild | Moderate | Severe | Very severe |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Not at all | A little bit | Moderately | Quite a bit | Extremely |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
b Have you been very nervous?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
c Have you felt so down in the dumps that nothing could cheer you up?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
d Have you felt calm and peaceful?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
e Did you have a lot of energy?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
f Have you felt downhearted and depressed?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
g Did you feel worn out?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
h Have you been happy?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
i Did you feel tired?	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

11. How TRUE or FALSE is each of the following statements for you?

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
--------------------	----------------	---------------	-----------------	---------------------

A I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Confirmation/Disconfirmation Operationalized as Perspective Taking Ability Scale

(Koenig Kellas, Willers, & Trees, 2014)

Directions: Based on your communication with your family **about systemic lupus**, please rate the degree to which you think **on the whole, your family members** engage in the following behaviors. The scale ranges from 1 (strongly disagree) to 5 (strongly agree). In answering questions about family on this survey, please use your definition of family. In other words, family includes whomever you define as family in your life.

1	2	3	4	5
Strongly	Disagree	Neutral	Agree	Strongly
Disagree				Agree

1. My family is attentive to me during conversations about systemic lupus.

1 2 3 4 5

2. My family listens to me when I talk in these conversations.

1 2 3 4 5

3. My family members are disengaged (do not pay attention) during our interactions about the systemic lupus.

1 2 3 4 5

4. My family members contribute relevant information to our conversations about systemic lupus.

1 2 3 4 5

5. My family helps me say what I want to say.

1 2 3 4 5

6. My family members are self-centered during our conversations about the ongoing conflict.

1 2 3 4 5

7. My family members ask me questions at appropriate times during these interactions.

1 2 3 4 5

8. My family members and I are in sync during conversations about systemic lupus.

1 2 3 4 5

9. My conversations about systemic lupus in my family feel disjointed.

1 2 3 4 5

10. My family gives me plenty of space to talk.

1 2 3 4 5

11. My family lets me talk about my experience with systemic lupus.

1 2 3 4 5

12. My family members interrupt me when I am talking.

1 2 3 4 5

13. My family members seem to understand my feelings about systemic lupus.

1 2 3 4 5

14. My family members do a good job of acknowledging my experience with systemic lupus.

1 2 3 4 5

15. My family members do not do a good job acknowledging my experience with systemic lupus.

1 2 3 4 5

16. My family members are kind during these interactions.

1 2 3 4 5

17. My family members are respectful of me when I talk.

1 2 3 4 5

18. My family members use humor during these interactions.

1 2 3 4 5

19. My family members are sarcastic during interactions about systemic lupus.

1 2 3 4 5

Openness Avoidance Communicative Behaviors Directions: On a scale from 1-7 where 1 indicates strongly disagree and 7 indicates strongly agree, please rate the degree to

which the following statements describe your communication about SLE in your family. In answering questions about family on this survey, please use your definition of family. In other words, family includes whomever you define as family in your life

People in my family can talk openly to one another about SLE

1 2 3 4 5 6 7

People in my family can share their feelings (both good and bad)

1 2 3 4 5 6 7

People in my family can talk openly with me about SLE.

1 2 3 4 5 6 7

People in my family freely deal with issues about SLE that may be upsetting.

1 2 3 4 5 6 7

People in my family share SLE related problems with each other.

1 2 3 4 5 6 7

People in my family tell other family members when something is bothering them about SLE.

1 2 3 4 5 6 7

People in my family talk about SLE when I am experiencing a flare.

1 2 3 4 5 6 7

People in my family avoid talking about the physical struggle I have with SLE.

1 2 3 4 5 6 7

People in my family avoid talking about the medical implications of SLE.

1 2 3 4 5 6 7

People in my family avoid talking about the emotional struggle of SLE.

1 2 3 4 5 6 7

Now, please answer these questions again using the same scale, this time thinking about an ideal family. In other words, please notice that I am asking about your standards for your family and not about your family's current behaviors. I want to know how you think families should act. So, on a scale from 1-7 where 1 indicates strongly disagree and 7 indicates strongly agree, please rate the degree to which the following statements describe ideal communication about SLE in families. In answering questions about family on this survey, please use your definition of family. In other words, family includes whomever you define as family in your life.

People in families should talk openly to one another about SLE

1 2 3 4 5 6 7

People in families should be able to share their feelings (both good and bad)

1 2 3 4 5 6 7

People in families should be able to talk openly with me about SLE.

1 2 3 4 5 6 7

People in families should freely deal with issues about SLE that may be upsetting.

1 2 3 4 5 6 7

People in families should share SLE related problems with each other.

1 2 3 4 5 6 7

People in families should tell other family members when something is bothering them about SLE.

1 2 3 4 5 6 7

People in families should talk about SLE when someone is experiencing a flare.

1 2 3 4 5 6 7

People in families should avoid talking about the physical struggle of SLE.

1 2 3 4 5 6 7

People in families should avoid talking about the medical implications of SLE.

1 2 3 4 5 6 7

People in families should avoid talking about the emotional struggle of SLE.

1 2 3 4 5 6 7

Self-Management Behaviors (created for this study based on Wallace, 2008)

Directions: On a scale of 1-7 please rate the degree to which the following statements describe your management of systemic lupus.

1: Not applicable

2: Never

3: Sometimes

4: Half the Time

5: Frequently

6: Most of the Time

7: Always

(1) Lifestyle

- a. I avoid sun exposure and wear sunscreen when I am in the sun.
- b. I strive to maintain a healthy, balanced diet.
- c. I strive to exercise within my capabilities regularly.
- d. I strive to ensure I get enough rest to manage my condition.

(2) Regular Physician Care

- a. I maintain a regular appointment schedule with physician
- b. I communicate new or unusual symptoms to my physicians.
- c. I discuss the impact of disease on my life with physicians
- d. I discuss barriers to care with my physicians

(3) Treatment Plan Adherence

- a. I regularly take all medications prescribed by my physician to manage SLE.
- b. I consistently get infusions when my physician recommends this course of treatment.
- c. I undergo surgeries when my physician recommends this course of treatment.
- d. I generally follow my physicians' treatment recommendations to manage SLE.