

University of Denver

Digital Commons @ DU

---

Electronic Theses and Dissertations

Graduate Studies

---

1-1-2011

## Spiritual Direction with Women Who Have Autoimmune Diseases: A Model of Psychospiritual Care

Kelly Renee Arora  
*University of Denver*

Follow this and additional works at: <https://digitalcommons.du.edu/etd>



Part of the [Practical Theology Commons](#), and the [Religious Thought, Theology and Philosophy of Religion Commons](#)

---

### Recommended Citation

Arora, Kelly Renee, "Spiritual Direction with Women Who Have Autoimmune Diseases: A Model of Psychospiritual Care" (2011). *Electronic Theses and Dissertations*. 752.  
<https://digitalcommons.du.edu/etd/752>

This Dissertation is brought to you for free and open access by the Graduate Studies at Digital Commons @ DU. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Digital Commons @ DU. For more information, please contact [jennifer.cox@du.edu](mailto:jennifer.cox@du.edu), [dig-commons@du.edu](mailto:dig-commons@du.edu).

---

# Spiritual Direction with Women Who Have Autoimmune Diseases: A Model of Psychospiritual Care

## Abstract

Rheumatoid arthritis (RA), multiple sclerosis (MS), and systemic lupus erythematosus (lupus) are incurable autoimmune diseases affecting a growing number of people in the U.S. Women typically receive medical care for the physical effects of these diseases, but psychospiritual dimensions of illness experiences are often neglected. Common autoimmune illness experiences include delayed diagnosis; chronic pain, fatigue, depression; and liminality (being neither healthy nor sick). Women with RA, MS, and lupus also experience ongoing losses (which may be disenfranchised), such as losses of identity, relationships, self-agency, and spiritual beliefs and practices. As a result of ongoing experiences of suffering and loss, women can "get stuck" in spiritual struggles that negatively affect her overall health and well-being. Provisional theological claims about the psychospiritual needs of women with RA, MS, and lupus assert that they would benefit from ongoing (over the course of years) acknowledgment of losses and complex, contextual theological meaning making, tested through coping strategies and spiritual practices that help them establish and/or sustain well-integrated spiritualities and life-enhancing relationships with God/the transcendent (a naming convention that reflects diverse spiritualities and spiritual direction practices). Evaluation of medical, psychological, and pastoral caregiving approaches finds contemporary intercultural spiritual direction, grounded in the Christian tradition, to be an optimal context for long-term care that addresses these needs. A model of spiritual direction for women with autoimmune disorders calls for (1) spiritual directors informed by women's experiences of autoimmune disease and prepared to balance a woman's need to engage in transformative spiritual struggle with the risks posed by getting stuck in chronic struggles, (2) an intercultural and feminist approach that privileges women's experiences and understandings of illness and God/the transcendent, (3) ongoing complex and contextual theological meaning making through narrative and ritual practices that address the shifting perspectives of chronic illness (recurrent vacillation between illness-in-the-foreground and wellness-in-the-foreground), (4) attention to coping strategies and spiritual practices that enact life-enhancing understandings of illness and God/the transcendent, and (5) co-construction and performance of rituals that acknowledge losses and facilitate transitions between illness-in-the-foreground and wellness-in-the-foreground perspectives. This model of spiritual direction can be used in one-on-one or group settings.

## Document Type

Dissertation

## Degree Name

Ph.D.

## Department

Religious and Theological Studies

## First Advisor

Carrie Doehring, Ph.D.

## Second Advisor

Frank Seeburger

## Third Advisor

Deborah Creamer

---

**Keywords**

Autoimmune disease, Disenfranchised loss, Intercultural care, Meaning making, Spiritual direction, Theology

**Subject Categories**

Practical Theology | Religion | Religious Thought, Theology and Philosophy of Religion

**Publication Statement**

Copyright is held by the author. User is responsible for all copyright compliance.

SPIRITUAL DIRECTION WITH WOMEN WHO HAVE AUTOIMMUNE DISEASES:  
A MODEL OF PSYCHOSPIRITUAL CARE

---

A Dissertation

Presented to

the Dean and Faculty of the University of Denver  
and the Iliff School of Theology Joint PhD Program

University of Denver

---

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

---

by

Kelly R. Arora

June 2011

Advisor: Carrie Doehring, Ph.D.

©Copyright by Kelly R. Arora 2011

All Rights Reserved

Author: Kelly R. Arora  
Title: SPIRITUAL DIRECTION WITH WOMEN WHO HAVE AUTOIMMUNE DISEASES: A MODEL OF PSYCHOSPIRITUAL CARE  
Advisor: Carrie Doehring, Ph.D.  
Degree Date: June 2011

### **Abstract**

Rheumatoid arthritis (RA), multiple sclerosis (MS), and systemic lupus erythematosus (lupus) are incurable autoimmune diseases affecting a growing number of people in the U.S. Women typically receive medical care for the physical effects of these diseases, but psychospiritual dimensions of illness experiences are often neglected. Common autoimmune illness experiences include delayed diagnosis; chronic pain, fatigue, depression; and liminality (being neither healthy nor sick). Women with RA, MS, and lupus also experience ongoing losses (which may be disenfranchised), such as losses of identity, relationships, self-agency, and spiritual beliefs and practices. As a result of ongoing experiences of suffering and loss, women can “get stuck” in spiritual struggles that negatively affect her overall health and well-being. Provisional theological claims about the psychospiritual needs of women with RA, MS, and lupus assert that they would benefit from ongoing (over the course of years) acknowledgment of losses and complex, contextual theological meaning making, tested through coping strategies and spiritual practices that help them establish and/or sustain well-integrated spiritualities and life-enhancing relationships with God/the transcendent (a naming convention that reflects diverse spiritualities and spiritual direction practices). Evaluation of medical, psychological, and pastoral caregiving approaches finds contemporary intercultural spiritual direction, grounded in the Christian tradition, to be an optimal context for long-term care that addresses these needs. A model of spiritual direction for women with

autoimmune disorders calls for (1) spiritual directors informed by women's experiences of autoimmune disease and prepared to balance a woman's need to engage in transformative spiritual struggle with the risks posed by getting stuck in chronic struggles, (2) an intercultural and feminist approach that privileges women's experiences and understandings of illness and God/the transcendent, (3) ongoing complex and contextual theological meaning making through narrative and ritual practices that address the shifting perspectives of chronic illness (recurrent vacillation between illness-in-the-foreground and wellness-in-the-foreground), (4) attention to coping strategies and spiritual practices that enact life-enhancing understandings of illness and God/the transcendent, and (5) co-construction and performance of rituals that acknowledge losses and facilitate transitions between illness-in-the-foreground and wellness-in-the-foreground perspectives. This model of spiritual direction can be used in one-on-one or group settings.

## Acknowledgements

I often thought of this dissertation as a mental marathon. Thankfully, I did not travel the distance alone. I will be forever grateful to my coaches, support team, and cheering section—the people who made it possible for me to cross the finish line. I am particularly thankful for Carrie Doehring, who expertly coached me through every step of my doctoral journey. Carrie, your contributions to my professional and personal formation are beyond measure! An outstanding dissertation committee shaped my ideas and writing. Carrie, Debbie Creamer, and Frank Seeburger, I deeply appreciate your timely and helpful feedback. I would not be where or who I am today without your support and mentorship. My family was absolutely critical to the success of this project. Nitu, Katie, and Alex, thank you for giving me quiet time to think and write, helping me study for comps, listening to my ideas, believing in me on my worst days, and celebrating with me on the best days. You made every keystroke possible. Mom and Kirk, thanks for always encouraging me to pursue my dreams. Your cheers from the sidelines boosted my spirits every day. I offer a special thanks to my spiritual director Linda. Thank you for years of listening and for helping me to make meaning of my world, stay in touch with my authentic self, and connect with God in times of confusion and clarity. Kerri, we have been friends since the first step of this journey. You've been a wonderful friend through it all, and your skillful proofing made it possible for me to finish strong. Betsy, and Jamie, I am honored to know you as colleagues and dear friends. I will always be grateful for your ever-present support. And, to all of my friends in the Ph.D. Ladies lunch group: thanks for sharing this experience with me. I will be waiting for you at the finish line!



## Table of Contents

Chapter One: Psychospiritual Care and Chronic Illness.....	1
Methodology.....	6
Pastoral theological context.....	8
Definitions.....	11
Intercultural care.....	20
Revised critical correlational method.....	22
Chapter Preview.....	26
Chapter Two: Thick Description, Disenfranchised Losses, and Spiritual Struggles.....	29
Autoimmune Diseases.....	32
Disease perspective: Rheumatoid arthritis.....	33
Disease perspective: Multiple sclerosis.....	35
Disease perspective: Systemic lupus erythematosus.....	37
Shared illness experience: Delayed diagnosis.....	38
Shared illness experiences: Pain, fatigue, and depression.....	41
Shared illness experience: Liminality.....	45
Disenfranchised Losses Associated with RA, MS, and Lupus.....	48
Identity losses.....	51
Relationship losses.....	59
Loss of self-agency.....	65
Spiritual losses.....	71
Spiritual Struggles, Health and Well-Being.....	75
Summary.....	80
Chapter Three: Theological Understandings of Chronic Illness.....	82
Meaning Making and Chronic Illness.....	84
Toward Theological Claims about Chronic Illness.....	89
Disability theologies.....	91
Paradigms for understanding suffering.....	95
Models of Understanding Chronic Illness.....	97
Metaphors for chronic illness.....	98
Moral model of understanding illness.....	102
Biomedical model of understanding illness.....	106
Social model of understanding illness.....	111
Provisional Constructive Theological Claims about Chronic Illness.....	115
Chapter Four: Psychospiritual Care for Women with RA, MS, and Lupus.....	119
Evaluation of Three Approaches to Care.....	121
Evaluation of biomedical care.....	121
Evaluation of psychological care.....	126
Evaluation of pastoral approaches to care.....	127
Spiritual Direction as an Approach to Care.....	132
The practice of spiritual direction in the Christian tradition.....	134

Narrative, contextual, and collaborative dimensions.....	146
Summary .....	154
Chapter Five: A Model of Spiritual Direction for Women with Autoimmune Diseases	156
An Explicitly Intercultural Approach to Care.....	158
Narratives, Coping Strategies, and Spiritual Practices .....	162
Narratives.....	163
Coping strategies and spiritual practices.....	167
Using Ritual with Women Who Have Autoimmune Diseases .....	172
Guidelines for ritual construction and practice.....	174
Illness-in-the-foreground and wellness-in-the-foreground perspectives.	175
Facilitating illness and wellness perspective shifts.....	178
Acknowledging disenfranchised losses. ....	182
A Model of Spiritual Direction Summarized.....	188
Informed spiritual directors.....	189
Intercultural and feminist approach to care. ....	190
Complex and contextual meaning making.....	190
Attention to coping strategies and spiritual practices. ....	191
Rituals to negotiate shifting perspectives and acknowledge losses. ....	191
The Future .....	192
References.....	196
Appendix.....	222

## **Chapter One: Psychospiritual Care and Chronic Illness**

When I was diagnosed with rheumatoid arthritis (RA) fourteen years ago, my doctor told me that this incurable autoimmune disease would require constant medical attention to monitor the progression of joint deterioration, watch my liver for signs of damage from toxic but necessary medications, and manage chronic pain and fatigue. What she said was accurate; it was also incomplete. She did not tell me how much psychological and spiritual energy the disease would also require. For example, I did not know that I would need to redefine my personal and professional goals in light of limited energy reserves or that there would be days when RA pain and fatigue would make it difficult to be a loving spouse or compassionate caregiver. My doctor did not tell me I would need to continually give up cherished activities, like standing on my head in a favorite yoga posture (my body weight threatened to destroy the increasingly fragile joints in my neck) or kneeling to pray in Mass (pain in my knees makes this posture intolerable). No, she did not tell me that I would spend the rest of my life trying to balance the demands of this disease with the desires of my heart. My doctor may have known these things, but I doubt it. She does not have RA; she has a medical degree, x-rays, medications, laboratory tests, and the desire to optimize my physical functionality. She understands my *disease*, but I do not think she understands my *illness*.

As I came to understand the critical differences between disease and illness, I recognized that I needed to find support for the psychospiritual dimensions of chronic

illness outside of the biomedical arena. Today my doctor and I care for the disease of RA, manifested primarily in physical challenges; my spiritual director and I care for the illness experiences, manifested in psychospiritual challenges. Every month, for eleven years and counting, my spiritual director and I talk about the ways RA affects my life—particularly my spiritual life, as that is the focus of the spiritual direction relationship.<sup>1</sup> Conversely, we also talk about the ways my spiritual life—my relationship with God, spiritual beliefs, and spiritual practices—affects how I understand and live with this unpredictable condition. I firmly believe that my sense of well-being in mind, body, and spirit is in large measure due to the hour spent in spiritual direction each month.

Rheumatoid arthritis is an autoimmune disease, one of a number of incurable conditions in which a person's immune system wages war against parts of the body as if they were foreign entities. Autoimmune disorders affect 14 to 22 million Americans (approximately eight percent of the population), most of whom are women. Every day in the United States, thousands of women with autoimmune diseases receive care for their bodies, but their psychospiritual needs are often neglected. Some women with autoimmune conditions undoubtedly find effective ways to cope with psychospiritual concerns, but there are also women who would benefit, as I have, from additional care for these dimensions of chronic illness.

My thesis is that contemporary intercultural spiritual direction, grounded in the Christian tradition, provides the framework for a long-term (over the course of years) approach to care that focuses on a woman's relationship with God/the transcendent<sup>2</sup> in

---

<sup>1</sup> I describe the practice of spiritual direction in detail in Chapter Four.

<sup>2</sup> See **Definitions** in this chapter.

ways that meet the unique psychospiritual needs of women who have autoimmune diseases—especially rheumatoid arthritis, multiple sclerosis (MS), and systemic lupus erythematosus (lupus). Some women might not identify themselves as “spiritual” or “religious.” However, if their illness experiences raise questions of meaning, or interfere with their sense of connection to that which is transcendent in their lives (e.g., God), then—as I define *spirituality*<sup>3</sup> in this dissertation—I believe they have psychospiritual concerns that would benefit from the relational focus on God/the transcendent at the heart of spiritual direction.

It is likely that women with any number of chronic health conditions experience similar struggles, and there is value in studying chronic illnesses in aggregate to address commonalities (Pattison, 1989, p. 16; Thorne & Paterson, 1998). However, *chronic disease* en masse encompasses such a broad spectrum of physical conditions with diverse characteristics that it is beyond the scope of this dissertation. Therefore, I focus on three autoimmune diseases with similar characteristics: rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus.<sup>4</sup> I also focus on *women* in the United States who have these conditions. Concentrating on this population allows me to draw on my personal story of living with rheumatoid arthritis and my experiences as a spiritual caregiver for other women who have autoimmune diseases. Given that the majority of people with RA, MS, and lupus are women, medical and psychological literature on these diseases is also generally more reflective of women’s experiences. The preponderance of this research has been conducted in Westernized countries that rely on biomedicine as their primary

---

<sup>3</sup> See **Definitions** in this chapter.

<sup>4</sup> Chapter Two provides a thick description of life with RA, MS, and lupus from a woman’s perspective.

approach to health care for these disorders, and this is an important point as I consider the most appropriate context for addressing a woman's psychospiritual needs.<sup>5</sup>

Attention to autoimmune disease is important because each year medical, psychological, and spiritual caregivers can expect to encounter a growing number of women who have these conditions (Grytten et al., 2006; "Increasing incidence of rheumatoid arthritis in women," 2008; Uramoto, 1999). In fact, the RAND Corporation projects that nearly half the population in the United States will have at least one chronic disease by the year 2030 ("Chronic disease fact sheet," 2008, p. 12). In addition, chronic pain—one of the most common characteristics of autoimmune disease and the most common reason for people in the U.S. to seek medical care—precipitates spiritual struggles (e.g., Underwood, 2006, pp. 3-4). In the future, caregivers can expect to see more careseekers who need help because of chronic health conditions or because their suffering is exacerbated by chronic illness experiences.

My personal experience affirms what psychological literature and pastoral care literature assert: it is very difficult for women with RA, MS, or lupus to find health care that responds to the full lived reality of chronic illness experiences. Women with acute physiological conditions that can be quickly resolved are usually able to find adequate care within the dominant biomedical system. Short-lived health problems do not typically generate ongoing losses or psychospiritual struggles, unless these conditions lead to disability. However, the biomedical model's short-term, problem-centered focus on curing does little to provide a holistic healing context for the relief of ongoing psychospiritual suffering associated with chronic diseases. Nevertheless, women with

---

<sup>5</sup> This evaluation is found in Chapter Four.

autoimmune diseases typically rely on medical professionals as their only caregivers. While medical care is necessary to manage the physiological aspects of disease,<sup>6</sup> members of the medical community generally are not equipped, available, or eager to discuss spiritual issues with their patients (Badaracco, 2007, pp. 120-121).

Women with RA, MS, and lupus may also find it difficult to discuss spiritual concerns with psychological counseling professionals, who typically do not explicitly address spirituality with their clients.<sup>7</sup> Even though spiritually-integrated psychotherapy groups address spiritual concerns, they usually use a short-term format (e.g., 6-10 weeks) that does not provide ongoing opportunities for women to focus on their evolving relationships with God/the transcendent (Pargament, 2007, p. 325). Pastoral care, pastoral counseling, and chaplaincy explicitly include spiritual guidance, but they are also short-term care strategies (i.e., often one conversation and rarely more than eight sessions) that do not provide ongoing attention to a careseeker's relationship with God/the transcendent. Spiritual direction, however, offers the type of long-term psychospiritual focus on how a woman's relationship with God/the transcendent is formed and informed by her illness experiences. This long-term relational focus of spiritual direction—characterized by the quintessential spiritual direction question Where is God/the transcendent in this?—distinguishes spiritual direction from all other kinds of care.

The model of spiritual direction I propose facilitates a healing relationship between women with RA, MS, and lupus and their understandings of God/the

---

<sup>6</sup> Chronic diseases often necessitate frequent visits to healthcare professionals to monitor patient progress and control the effects and progression of the disease.

<sup>7</sup> Psychologist Kenneth Pargament, psychiatrist Len Sperry, and psychologist Edward Shafranske are among psychotherapists attempting to change this professional norm.

transcendent. This relationship heals through the acknowledgment of ongoing losses and complex, contextual theological meaning making that is tested through coping strategies and spiritual practices. Spiritual direction helps women establish and sustain well-integrated spiritualities and life-enhancing relationships with God/the transcendent.

## **Methodology**

In addition to my personal experiences with chronic illness and spiritual direction, I have had the privilege of being a companion on the spiritual journeys of a number of women who have RA, MS, or lupus. Through the sharing of our collective stories—within and outside of the context of spiritual direction—I have gained further insights into the paradox of living in a liminal space where a person is neither healthy nor sick and, at the same time, is both healthy and sick. These experiences of spiritual care and community, while not elaborated within this dissertation, served as the catalyst for my reflections on and analysis of chronic illness from my perspectives as a spiritual director and as a pastoral theologian. Pastoral theological reflection

*always begins with a human situation* (the “case” at hand), not an abstract idea, image, doctrinal proposition, or social or psychological theory to which cases are then made to fit. . . . [Pastoral theological] reflection begins with the richness of the real person—the “living human document.” (Cooper-White, 2004, p. 74, emphasis in original)

In the case of this dissertation project, the human situation that initially served as catalyst for reflection was my own.

As a living human document, I recognize that I bring to this process of pastoral theological reflection certain biases. I am a middle-aged, white (of Germanic and Swedish descent), heterosexual, upper-middle-class, wife, mother, sister, daughter,



academic, spiritual caregiver who has an autoimmune disease. Although currently a member of the Roman Catholic Church, I arrived at this faith community by way of the Missouri Synod Lutheran Church, Buddhism, the Universal Unitarian tradition, the United Methodist Church, and the Episcopal Church. Educated as an industrial engineer, I worked in the corporate world of telecommunications for eleven years before transitioning to a full-time commitment as stay-at-home mother and volunteer church leader. In the last ten years, I have focused my energies on spiritual direction (giving and receiving in the Christian tradition) and enhancing my academic credentials as I completed a master's degree in religion and pursued doctoral work in religious and theological studies. Generally speaking, I consider my diverse background to be a benefit when it comes to understanding the ways in which women with chronic illnesses experience losses and contradictory expectations (from self and others). However, I also recognize that my social privileges limit my understandings of other women's experiences in the many ways that I do not reflect their identities as younger, older, homosexual, single, women of color, etc.

As I will point out in the following chapters, medical literature on autoimmune diseases, as well as religion and health literature and research in general, have been critiqued for the lack of social diversity in their study populations (e.g., Coruh, Ayele, Pugh, & Mulligan, 2005; Koenig, McCullough, & Larson, 2001; M. Townsend, Kladder, & Mulligan, 2002). In addition, my spiritual direction experience and the proposed model of spiritual direction introduce bias with their connection to the historical Christian tradition. One way I address concerns about the ways my social identity and the bodies of literature used in this dissertation impose limitations upon this project is to use a feminist

and intercultural approach to spiritual direction that privileges each woman's particular beliefs, experiences, and the constructed world in which she has those experiences.

Although I use a variety of medical and psychological literature to develop a "thick description" of what might constitute a typical woman's experience of chronic illness, I recognize that this description will be too general for some readers and too particular for others. I do not attempt to speak for all women who have autoimmune diseases, but I name common characteristics of the chronic illness experience that may catalyze or exacerbate spiritual struggles. I also describe disenfranchised losses associated with chronic illness, and I predict that these losses will resonate with many women who have autoimmune conditions.

I hope that one day we will hear the voices of many more women contributing to this work. That may happen as women participate in the model of spiritual direction described here, as they critique or expand this model, or as they offer alternative healing strategies of their own. For now, this dissertation brings together voices of women who have RA, MS, and lupus from psychology, medicine, religion, and spirituality literature in order to better understand and address the experiences of women with chronic health conditions.

### **Pastoral theological context.**

Pastoral theology provides the context for a rich conversation among pastoral and spiritual practices and cognate secular disciplines, a conversation that leads to critical reflection in order to develop new theological and psychological resources for spiritual care. This dissertation assumes that science (namely medicine and psychology) and

religion (more broadly, spirituality) can engage in a mutually constructive dialogue whereby neither perspective seeks to triumph over the other, and the unique perspectives of each field do not merge together. Rather, dialogue “emphasizes the differences between science and religion, even as it hopes to find ways each might influence the other” (Miller-McLemore, 2010, p. 73).<sup>8</sup>

The need for a pastoral theology on illness that fully engages these cognate disciplines was recognized as early as 1989, when Pattison noted:

Unlike the liberation theologians, the [pastoral theologians working on illness] do not draw widely on the resources of philosophy, theology, the social sciences or medical science to develop different practical responses and theological attitudes to different situations. . . . [T]he whole area of healing and illness is a crucial nexus for the veracity and relevance of Christianity and Christian theology. It deserves a more active intellectual engagement. (pp. 64-65)

This dissertation addresses the need for pastoral theologians to engage in the spirituality/religion and health dialogue, a need that continues to grow as our colleagues in the medical field continue to amass a sizeable body of literature exploring the relevance of religious and spiritual beliefs and practices to holistic health care (Koenig & McCullough, in press). As I will describe in the following section, definitions of key terms remain in flux. Theologians obviously have something to contribute to definitions of *religion* and *spirituality*, but we should also take a keen interest in definitions of *health*, *illness*, *healing*, and *well-being* as spiritual dimensions of these states of being are highly relevant to care of the whole person. In relation to definitional work, a public

---

<sup>8</sup> For a more detailed discussion of *dialogue*, see Barbour’s (2000) description of four ways for religion and science to be relationship (conflict, independence, dialogue, and integration).

theology of chronic illness would also help guide spiritual caregivers in the coming years.<sup>9</sup>

Another catalyst for active pastoral theological participation in the spirituality/religion and health dialogue is the growing interest among members of the psychological community to develop spiritually-integrated psychotherapeutic approaches to care (e.g., Pargament, 2007; Sperry & Shafranske, 2005). Their work would benefit from more sophisticated understandings of theology and approaches to spiritual care so they do not exacerbate spiritual struggles. For example, psychological caregivers' assumptions about the ways careseekers construct their religious/spiritual worlds might result in imposing on careseekers life-diminishing understandings of God/the transcendent, religion/spirituality, or illness. A shared concern for careseeker well-being opens the door for collaboration between pastoral theologians and our colleagues in psychology.

Other spiritual caregivers have also indicated a desire to address the relationship between spirituality and health. For example, spiritual directors are actively working to establish collaborative relationships with medical professionals to offer holistic care in a variety of settings (e.g., Puchalski et al., 2009). Given that the work of pastoral theology arises from and returns to the practice of spiritual caregiving, pastoral theologians need to assert our voices in current discussions about holistic care, beginning with basic definitions.

---

<sup>9</sup> Developing a public theology of chronic illness is an important project for pastoral theologians, but it is beyond the scope of this dissertation.

## **Definitions.**

Pastoral theologians strive to be methodologically thorough, and attention to method includes awareness of embedded definitions. Because this dissertation engages vocabulary from a number of fields where terms occasionally overlap—and even contradict each other—definitions are all the more important. In Chapter Two, I provide detailed descriptions of rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus. Here I introduce definitions of *disease*, *disability*, *illness*, *healing*, *curing*, *suffering*, *health*, *pain*, *well-being*, *religion*, *spirituality*, *God/the transcendent*, and *spiritual struggle*.

In this dissertation, *disease* describes a medically-defined condition in which physiological structure and/or function are impaired (E. J. Cassell, 2004/1991, p. 47). In a traditional biomedical context, diseases are the focus of the caregiver's "gaze." As a result, biomedical caregivers tend to perceive patients as specimens. *Chronic diseases* are those health conditions for which medical science does not currently have a cure, and science may not even—as in the case of RA, MS, and lupus—have an identifiable cause. In some cases, diseases lead to temporary or permanent *disability*, or the loss of physiological or other function (Smart & Smart, 2006, pp. 31-32).<sup>10</sup> I will explore understandings of disability related to chronic illness in greater detail in Chapter Three.

I use *illness* to describe the subjective experience of living with disease (Kleinman, 1988). This experience extends beyond the physical nature of disease to include its psychological, cognitive, and spiritual dimensions. Illness experiences include

---

<sup>10</sup> Not every person with the same disease, or even the same consequences of a disease, considers herself disabled, even if she is functionally impaired.

not only the person with the medical malady, but also members of her family and extended community.

The term *healing* is obviously part of the medical lexicon, but the term also has a particular meaning within the context of pastoral theology. In 1958, Seward Hiltner demarcated the field of pastoral theology as “the theological theory resulting from study of the operations of pastor and church approached from the shepherding perspective and studied under the subheadings of *healing*, sustaining, and guiding” (p. 69, emphasis added). Hiltner defined *healing* as “the restoration of functional wholeness that has been impaired as to direction and/or schedule” (p. 90). Hiltner’s reference to “functional wholeness” resonates more closely to the way I use the term *curing* in this dissertation, where *curing* is the eradication of disease. I find Hiltner’s definition of *healing* to be inadequate in the context of chronic illness.

Hiltner goes on to define *sustaining* as “the ministry of support and encouragement through standing by when what had been a whole has been broken or impaired and is incapable of total situational restoration, or at least not now” (p. 116). If his definitions of *healing* and *sustaining* were integrated, the result would be more inclusive of the lived reality of chronic illness in which people are able to experience wholeness in spite of functional limitations and in spite of their unlikely restoration to a former state of health. Rather than rework these definitions here, I note that pastoral theologians would benefit from rethinking Hiltner’s definitions as they are embedded in understandings of our field.

For purposes of this dissertation, I opt for a simpler definition: *healing* is relief from suffering, where *suffering* is physical, emotional, and/or spiritual distress that may

or may not be related to pain. The process of healing helps a person move toward wholeness through the restoration of relational harmony with self (i.e., reintegration of body, mind, and spirit), others, the environment, and God/the transcendent. I choose this definition because it acknowledges that healing can occur even in the presence of disease (Egnew, 2005, p. 255), it implies a holistic understanding of the person, and it resonates with health care professionals and patients alike (e.g., Hsu, Phillips, Sherman, Hawkes, & Cherkin, 2008).

This dissertation extends the World Health Organization's definition of *health* from "the physical, social, and psychological well-being of the individual" (Warren, 2007, p. 74) to explicitly include the spiritual dimension of the person. Additionally, *health* is understood as a fluid, rather than a discrete, state of being. This nuanced definition of *health* is important because not every woman living with an incurable disease considers herself to be *unhealthy* or *sick* or *ill* at any given moment. As described in greater detail in Chapter Two, chronic illness is experienced as a liminal state of being that defies consistent location along the *healthy-unhealthy* continuum; this is true across women and within an individual woman's experience of autoimmune disease.

*Pain* has been defined by the International Association for the Study of Pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" ("IASP pain terminology," 2010). This definition describes an experience that straddles the line of objectivity-subjectivity, an experience that

is uniquely defined for each individual . . . For pain is not an objective and visible clinical finding in the manner of a fractured femur or purulent sputum. Rather, pain is a perception communicated through both language and nonverbal

behaviors such as tears or agitation. As such, pain is intrinsically subjective and inaccessible, “that which cannot be denied, and that which cannot be confirmed” [Scarry, 1985]. (Magid, 2000, p. 114)

To some degree, women who have RA, MS, and lupus share physical experiences of chronic pain, fatigue, and malaise. In addition, many women with these diseases will experience distress as a result of psychological and spiritual consequences associated with their physical conditions. The ability of a woman to cope in life-enhancing ways with the (more or less) objective (e.g., pain, fatigue, and other physical symptoms) and the subjective (e.g., suffering) dimensions of chronic illness contributes to her overall sense of *well-being*.

For the purposes of this project, *well-being* is a subjective measure of how a person experiences inner and outer harmony in all dimensions of life. “Well-being to some extent has to do with being well, but it has more to do with existing well in the midst of whatever life brings to one. Thus there can be well-being in the midst of suffering” (Freeman, 1998, p. 8).<sup>11</sup> A person can experience well-being with or without curing, and a person’s well-being would be enhanced in at least one dimension, albeit perhaps not holistically, when healing brings relief from suffering.

The subjective aspects of illness, health, and well-being play a greater role in describing the “success” of spiritual care than they do in medical care of the body or psyche where more objective measures of positive and negative states of being are possible. Within the medical community, there is a certain level of mistrust regarding such subjective or “fuzzy” terms. This frustration extends to the fuzzy terms *religion* and *spirituality* (Zinnbauer et al., 1997).

---

<sup>11</sup> For an illustration from medical literature of well-being in the midst of suffering, see Koenig’s (2002a) description of his encounter with an 83-year-old woman who has strong religious beliefs.



Scholars in psychology and medicine are grappling with definitions of *religion* and *spirituality* (e.g., Anderson, 2001; Coruh et al., 2005; Pargament, 2007). For pastoral and practical theologians, the challenge of defining these terms is translating the complex and diverse historical ways these terms have been understood by scholars of religious and theological studies into terms that are relevant and compelling to members of the health professions today. Challenging as the work may be, it behooves us to participate: “If those of us serving in spiritual and pastoral care do not, others will create the definitions for us” (Bartel, 2004, p. 187).

The intercultural approach that I use in this dissertation further complexifies the search for relevant and meaningful definitions of religion and spirituality because of the ways it values differences and raises questions about our need for commonalities and “one size fits all” universal definitions of *religion* and *spirituality*. Using the scholarship of the comparative study of religions, pastoral theologians can help health professionals become aware of the dangers of assuming there is a common core to all religions of the world. This implicit universalist approach leads health care professionals to focus on commonalities among their personal and/or cultural experiences of religion and the lived experience of religion and spirituality that patients or clients bring to the caregiving relationship (Doehring, 2010).

Universalist approaches are often embedded in language used when speaking with patients or clients, particularly language that names the ways people refer to that which is divine, sacred, transcendent, or ultimate within the context of their religious/spiritual world-making. I am aware of the inadequacy of any naming convention for that which cannot be fully understood or described. That said, in this dissertation, I use *God/the*

*transcendent* to refer to God, G\_d, Allah, the sacred, the ultimate, and other terms naming that which is at the heart of a person's spirituality (definition forthcoming). The use of *God* acknowledges the Christian tradition from which the proposed model of spiritual direction comes, and it represents understandings of a divine force active in the lives of people today. *The transcendent* serves as a proxy for all other terms, and it reflects understandings and spiritual direction practices from other traditions, such as Judaism<sup>12</sup> and Buddhism.<sup>13</sup> The use of *God* and *the transcendent* together is a reminder that I am using an intercultural approach to develop a model of spiritual direction that is mindful of the contextual nature of spirituality within the diverse population of women who have autoimmune diseases.

In thinking about definitions of *religion* and *spirituality*, there is some agreement among researchers and members of the public that *religion* refers to public and private organized systems of beliefs, practices, rituals, and symbols in relation to God/the transcendent (e.g., Zinnbauer et al., 1997). Spirituality/religion and health researchers also recognize that an individual may engage in practices traditionally associated with

---

<sup>12</sup> In Jewish spiritual direction, the spiritual journey typically reflects a person's desire for greater awareness of God's presence in all of life. Jewish spiritual director Amy Eilberg (2005) notes, "there are abundant texts in classical Jewish sources that describe a personal, supernatural, loving, and active God. . . . However, it is relatively rare to find a Jewish seeker, or even a Jewish spiritual companion, who is entirely comfortable with this theology. It is even more surprising to find a Jew who can extend this belief to an affirmation of God's being personally active in his or her individual life. For most Jews, such a notion seems threatening, not authentically Jewish, and therefore suspect" (p. 27). In Jewish spiritual direction, the quintessential question "Where is God in this?" needs to be reframed "as a reminder, an invitation to drop into the universal truth of God's omnipresence in every moment and every experience" (p. 31).

<sup>13</sup> In Buddhist spiritual direction, the spiritual journey is a movement toward fuller realization of desirable transcendent qualities. In the words of one Buddhist spiritual guide, spiritual direction in this tradition means "asking for assistance with aligning ourselves with what is real and dissolving the obscurities we have created in our lives that keep us from that goal . . . The whole of our Buddhist practice is for the development of love and compassion for all beings . . . Specific skills are developed over time . . . and may be assisted through spiritual direction" (Taylor, 2007, p. 48).

religion (e.g., meditation) without the desire to establish, maintain, or strengthen a relationship with God/the transcendent.

*Spirituality* is a more difficult term to define (and to operationalize for research purposes) because it is commonly used as an umbrella expression for the infinite variety of unique amalgams of complex personal beliefs and practices in relation to God/the transcendent (Clarke, 2009; Coruh et al., 2005; A. Edwards, Pang, Shiu, & Chan, 2010; Koenig et al., 2001; Pargament, 2007; Tanyi, 2002; M. Townsend et al., 2002). The degree to which definitions of *religion* and *spirituality* overlap makes it even more difficult to discern one term from the other. This observation is illustrated by the fact that 74 percent of participants in one empirical study identified themselves as *both* religious and spiritual (Pargament, 2007).

Because these terms are frequently used interchangeably, but with much confusion, some researchers in the field of spirituality/religion and health (e.g., Hall, Meador, & Koenig, 2008) suggest that *religion* be used for research purposes because it best represents traditional understandings of the concepts and terms typically employed in empirical studies (e.g., attendance at faith community worship services, identification of religious affiliation or denomination) and because the term can be more narrowly and, therefore, clearly defined.<sup>14</sup> In addition, some scholars believe *spirituality* may be a trendy term that lacks longevity (Zinnbauer et al., 1997) or a “glow word” (Bregman, 2004, p. 157)—a word with positive connotations and vague meaning that makes people feel better by association. In fact, *spirituality* often loses useful meaning altogether (McSherry & Cash, 2004). On the other hand, the broad appeal of the term resonates with

---

<sup>14</sup> For this reason, I now refer to this field of research as “religion and health.”

many people within the practical context of caregiving relationships. As a result, *spirituality* may be most appropriate for use within a caregiving relationship (Hall et al., 2008).

In this dissertation, *spirituality* is

distinguished from other things—humanism, values, morals, and mental health—by its connection to the transcendent. The transcendent is that which is outside of the self, and yet also with the self—and in Western traditions is called God, Allah, HaShem, or a Higher Power, and in Eastern traditions is called Ultimate truth or Reality, Vishnu, Krishna, or Buddha. Spirituality is intimately connected to the supernatural and religion, although also extends beyond religion (and begins before it). Spirituality includes a search for the transcendent. (Koenig, 2010, p. 55)

An existential approach to defining spirituality, such as I am using, focuses on the process of meaning-making and the experience of self-transcendence:

Spiritual beliefs can also exist without a belief in a higher power as an individual can draw upon his/her own meaningful life experiences (Graham, Furr, Flowers, & Burke, 2001). . . . [and] each person finds his/her own way of being that is unique and personal, based on his/her life history, personal experiences, attributions, and understanding of spirituality. And yet, a common thread of spiritual transcendence serves to lift the spiritual believer out of his/her current time and place. (Gall & Grant, 2005, pp. 522, 529)

Spiritual direction may or may not occur in relationship to a particular religious community, thereby situating this practice within the broader realm of spirituality. However, because this dissertation offers a model of spiritual direction grounded in historical Christian practices of the discipline, religion is also relevant here. I acknowledge that Christian spiritual direction carries with it embedded beliefs about God, people, and their relationships. For example, Christian spiritual direction assumes God desires relationships with people, God continues to reveal God's self and God's desires in a multitude of ways, people have the ability to comprehend God's desires through a variety of experiences, and the relationship between God and an individual may change

over time. Using an explicitly intercultural approach to care (described in greater detail in Chapters Four and Five) diminishes the potential of spiritual directors imposing these embedded beliefs on careseekers.

This dissertation uses the term *spiritual struggle* to describe suffering or lack of well-being in relation to a person's spirituality. Traumatic life experiences (e.g., diagnosis with an incurable degenerative autoimmune disease) can trigger spiritual struggles when a person's meaning making is not able to account for suffering or when a person does not have a well-integrated spirituality (Pargament, Murray-Swank, Magyar, & Ano, 2005, pp. 251-252). A well-integrated spirituality consists of beliefs and practices working together in flexible and contextual ways to help a person sustain a relationship with God/the transcendent (Pargament, 2007, p. 136). It is important to note that

although limitations in one's spiritual orientation may lead to spiritual struggles, the problem here is not a lack of spirituality. Those who attach little importance to transcendent issues are likely to be spared spiritual turmoil. Spiritual struggles may have more to do with the quality of spirituality than the absolute level of spirituality. Still, even those with sturdy spiritual orienting systems are not immune to spiritual struggles. (Pargament, Murray-Swank, et al., 2005, p. 252)

Spiritual struggles may eventuate in positive experiences (e.g., life-enhancing transformation) and/or negative experiences (e.g., a sense of abandonment or isolation from God/the transcendent). Chronic spiritual struggles are of particular interest in this dissertation because they pose the greatest risk for negative health effects (Pargament, Koenig, Tarakeshwar, & Hahn, 2004; Pargament, Murray-Swank, et al., 2005; Trevino et al., 2010), and they have the potential to exacerbate the already challenging experience of an incurable disease. I will say more about the relationship between chronic spiritual struggles, health, and well-being in Chapter Two.

Today, pastoral theologians and caregivers recognize that the increasing popularity of the terms *spiritual* and *spirituality* also coincides with movement toward more contextually-sensitive models of care. An intercultural model of care is one contextual approach that helps caregivers attend to differences between their spiritual “world-making” (Doehring, 2010, p. 6) and their careseekers’ spiritual world-making.

### **Intercultural care.**

Mirroring public acceptance of *spiritual* and *spirituality*, pastoral caregivers have made subtle shifts toward replacing *pastoral care* with *spiritual care*. This development acknowledges a desire to provide more holistic care, diminishes embedded perceptions that care only takes place in Christian-to-Christian relationships, and extends the concept of *caregiver* to include laity as well as clergy (Anderson, 2001). Doehring (2010) explicitly uses *spiritual care* rather than *pastoral care*<sup>15</sup> within the context of the intercultural paradigm of care first described by Lartey (2003). In his description of the intercultural paradigm, Lartey “uses the term *intercultural* to push spiritual caregivers beyond recognition of diverse cultures to a critical awareness and engagement with that which is ‘other’ in careseekers” (p. 2, emphasis added). In Doehring’s work, the choice of *spiritual care* over *pastoral care* invites caregivers to specifically recognize diversity in religious and spiritual beliefs and practices.

Although I propose a model of spiritual direction that is grounded in the historical Christian tradition, the contemporary approach to spiritual care used within this model explicitly draws upon the phenomenological comparative approach to religions of the

---

<sup>15</sup> In this dissertation, I retain the use of *pastoral care* and *pastoral theology* to name academic disciplines and their associated bodies of literature.

world articulated in the Lartey/Doehring intercultural model of care. Using the extended intercultural model, this dissertation constructs a model of spiritual direction for women with autoimmune diseases where spiritual caregivers

[1] use a comparative approach to religion that highlights what is different about each person's religious faith . . . [2] cultivate a critical self awareness of who they are spiritually and theologically, so that they do not unwittingly impose their religious meanings-making and practices on those seeking care . . . [a process that de-centers and enables them to] [3] co-create contextual provisional meanings and ways of experiencing holiness. (Doehring, 2010, p. 3)

Although *intercultural care* is not explicitly named in spiritual direction literature, I believe most spiritual directors today demonstrate a phenomenological approach to care through the spiritual direction commitment to “not-knowing,” a practice that explicitly privileges the careseeker's experiences and beliefs (e.g., Arora, in press; Little, 2007).<sup>16</sup> In addition, most spiritual directors welcome everyone to the caregiving relationship, regardless of a careseeker's faith affiliation or lack of affiliation, and spiritual directors do not seek to “convert” careseekers to particular understandings of God/the transcendent or ways of living out their spirituality.<sup>17</sup>

In addition to attending to religious and spiritual differences between caregivers and careseekers, the model of spiritual direction I propose for women with autoimmune diseases also explicitly seeks to recognize differences between caregivers' and careseekers' illness experiences and meaning making. Caregivers who impose their own

---

<sup>16</sup> I describe the practice of not-knowing in Chapter Four.

<sup>17</sup> My personal experience with a number of spiritual directors over the years and my experiences with diverse groups of peers in supervisory relationships and in community settings where we have spoken about our practices testify to the validity of this assessment. Spiritual Directors International (SDI) strives to educate members of the global spiritual direction community about the diversity of ways in which people understand and relate to God/the transcendent. SDI regularly publishes such articles in *Presence: An International Journal of Spiritual Direction* (e.g., Addison, 2004), and it publishes books on diverse spiritual direction practices (e.g., Wagner, 2006).

beliefs about illness and disability on careseekers with chronic health conditions may exacerbate or disenfranchise the careseeker's illness-related losses and spiritual struggles.

The work of this dissertation seeks to enhance not only the dialogue between individual caregivers and careseekers in spiritual direction relationships; it also sets the stage for fruitful conversation among a number of communities committed to facilitating healing for women with RA, MS, and lupus. The revised correlational method of pastoral theology makes such a conversation possible.

### **Revised critical correlational method.**

Pastoral theology is a contextual dialogue between faith and culture (Hiltner, 1958, pp. 22-23), and it employs methodologies that respect “the distinctive norms and values of each ‘conversation partner’” (Ramsay, 2004, p. 5). In this dissertation, I use the pastoral theological method of revised critical correlation to bring the practices of intercultural spiritual care and spiritual direction into a mutually constructive conversation with theological, psychological, and medical literature on shared experiences and losses associated with autoimmune disease in women. This critical correlational process eventuates in provisional constructive theological claims about the psychospiritual needs of women with autoimmune diseases and the ways in which spiritual direction can address these needs.

In Chapter Two, I present a thick description of rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus from a woman's perspective. I primarily use women's stories presented in medical and psychological literature, and I augment these accounts with my own experiences. This method of reflecting on “living human



documents” attends to oft-marginalized voices of women with autoimmune diseases (E. Graham, Walton, & Ward, 2005, pp. 18-46). A pastoral theologian could stop at this point. However, the multi-disciplinary dialogue of the critical correlational method goes beyond reflection to develop a course of action for spiritual care that is driven by

the desire to undertake practical (ministerial) action, in response to felt need, that is relevant to its particular situation and explicitly informed by the values of faith. As it emerges from the crucible of correlative interpretation, theology articulates the narratives and metaphors of faith in new imperatives for transformative action. (E. Graham et al., 2005, p. 163)

Through dialogue, critical correlation facilitates the consideration of ways in which spiritual caregivers may need to re-envision care practices in light of psychological and medical understandings of chronic illness, and it helps me reflect on the ways in which medical and psychological care practices could be critically challenged by theological understandings of chronic illness.

I am mindful that the correlational method has been criticized for having an individualistic orientation (e.g., E. Graham et al., 2005, p. 168; Ramsay, 2004, p. 32). I address this weakness by intentionally bringing a communal contextual perspective (Patton, 1993) to bear on my reflections through the lenses of community-oriented feminist approaches to ritual and spiritual direction (Berry, 2009; Fischer, 1988; Guenther, 1992) and feminist approaches to pastoral care (Doehring, 1992, 1999; Neuger, 2001). Pastoral theology has also been critiqued by scholars of spirituality for privileging the Christian tradition (e.g., Schneiders, 2005a). In this dissertation, this tendency is addressed with the phenomenological interpretation of spiritual care in general and spiritual direction in particular. Although this dissertation is grounded in pastoral

theological methodology, it engages the field of spirituality, which has its own particular methodological approach.

*Pastoral theology and spirituality.*

Theology and spirituality have been described as two sides of the same coin: the study of faith and the life of faith (Schneiders, 2005b, p. 11). Commonalities between the two fields include their shared emphases on experience, critical reflection, multiple dialogue partners, and methodology (Liebert, 2005, pp. 84-85). These commonalities aside, theology and spirituality have different overarching goals: pastoral theology (and, by extension, pastoral care) is more problem-oriented, whereas spirituality (expressed, for example, in the practice of spiritual direction) is focused on a person's spiritual life and relationship with God/the transcendent, which may or may not include problem resolution (Liebert, 2005, p. 85). Both foci are important in this dissertation: the problem-orientation of pastoral theology prompts the search for approaches to spiritual care that meet the unique needs of women with autoimmune disorders, including the need to attend to the ways in which illness experiences and spirituality affect each other.

Pastoral theology and spirituality have distinct methodological approaches. As they engage in conversation with spirituality scholars and caregivers, pastoral theologians are aware that

pastoral methods must reflect broader definitions of care, including welcoming partners that reflect scopes of practice beyond those related to mental health. Attention to issues of spirituality will continue to be in the center of conversations about therapy, care, and counseling (McCarthy, 2002). Spiritual directors along with clinicians who research the role of spirituality must be partners in our pastoral theological work and in the practices of care we adopt. (Marshall, 2004, p. 148)

Spirituality scholars rely on a “hermeneutical approach” with a primary goal to “*understand* the phenomena of the Christian spiritual life as experience” (Schneiders, 2005a, p. 56, emphasis in original). With this approach, spirituality scholars employ thick description, critical analysis, and interpretation to come to better understandings of the spiritual life (Schneiders, 2005b, p. 6). A hermeneutical approach is useful in this dissertation when I develop a thick description of life with RA, MS, and lupus (Chapter Two) and engage in critical analysis of this description in order to construct theological claims about the psychospiritual needs of women who have these diseases (Chapter Three).

### ***Constructive theology.***

Taking a theologically sophisticated approach to spiritual direction, this dissertation constructs provisional theological<sup>18</sup> claims about a woman’s experience of autoimmune disease and the type of spiritual care that would best address her psychospiritual needs. This work takes seriously the assertion that it is the

constructive efforts of pastoral theology that will best serve pastoral care and counseling in the future. Theology needs to be retained, but not simply as a convenient conversation partner for application to situations and needs of communities and parishioners; rather theological inquiry and reflection must rest at the integral core of every constructive effort and every pastoral action. (Marshall, 2004, p. 137)

In this dissertation, provisional theological claims assert that the experience of autoimmune disease necessitates ongoing meaning making as well as acknowledgement

---

<sup>18</sup> Theology is often associated with the Christian tradition. In this dissertation, I use the term in its broadest sense to refer to structured ways of thinking about religious and spiritual truth claims, particularly moral claims implicit within understandings of illness and disability.

of ongoing losses. To support this work, women who live with RA, MS, and lupus need ambiguous and complex theological understandings of illness and suffering, enacted in coping strategies and spiritual practices, that address the liminal nature of chronic illness. In conversation with research on religious coping (e.g., Pargament, 1997, 2007), these theological claims are used to develop a model of spiritual direction to help women sustain life-enhancing and transform life-limiting spiritual beliefs, coping strategies, and spiritual practices as they live with and relate to God/the transcendent through their experiences of chronic illness.

### **Chapter Preview**

Chapter Two surveys psychological and medical literature to develop a thick description of how women with RA, MS, and lupus experience chronic illness. This depiction includes a medical overview of each disease as well as shared illness experiences of delayed diagnosis; chronic pain, fatigue, and depression; and liminality. The chapter then describes potential disenfranchised losses related to a woman's identity, relationships, self-agency, and spiritual beliefs and practices. Finally, research on the relationship between religion and health illuminates the ways in which spiritual struggles, coping strategies, and meaning making may affect a woman's health and well-being.

Chapter Three surveys pastoral care, psychological, and religious coping literature to describe ways meaning making emerges out of and affects the chronic illness experience. Disability theologies, disability studies literature, and theological paradigms for understanding suffering are used to examine underlying theological implications of three common models of understanding illness and disability. Then these theological

reflections are brought into conversation with the thick description of RA, MS, and lupus developed in Chapter Two in order to construct provisional theological claims about the psychospiritual needs of women with these autoimmune diseases.

Using the provisional theological claims developed in Chapter Three, Chapter Four evaluates biomedical, psychological, and pastoral approaches to care for women with RA, MS, and lupus. This evaluation demonstrates the need for intercultural spiritual direction as an approach to psychospiritual care that is uniquely suited to address the particular concerns of women with autoimmune diseases. The chapter describes spiritual direction as a narrative, contextual, and collaborative approach to care that focuses on a woman's relationship with God/the transcendent and supports complex theological meaning making, lament, acknowledgment of losses, intercultural care, and empowerment of women.

Chapter Five continues the work of Chapters Three and Four with a practical model of contemporary intercultural spiritual direction, grounded in the historical Christian tradition, for women with RA, MS, and lupus. The model calls spiritual directors to be informed by women's experiences of autoimmune disease and prepared to balance a woman's need to engage in transformative spiritual struggles with the risks posed by chronic spiritual struggles. The model uses an intercultural and feminist approach to spiritual direction that privileges women's experiences and understandings of illness and God/the transcendent. It also uses complex and contextual meaning making, through narrative and ritual practices, that takes into account losses and the recurring shifting perspectives of illness-in-the-foreground and wellness-in-the-foreground. Within this model, spiritual directors facilitate careseeker enactment of life-enhancing

understandings of illness and God/the transcendent through coping strategies and spiritual practices. Finally, spiritual directors using this model collaborate with careseekers to co-construct and perform rituals that acknowledge ongoing losses and facilitate life-enhancing transitions between illness-in-the-foreground and wellness-in-the-foreground perspectives. The dissertation concludes with remarks about the ways in which this work may contribute to the fields of spiritual direction, pastoral theology, psychology, and medicine.

In summary, this dissertation provides pastoral theologians, pastoral/spiritual caregivers, and health care professionals with an interdisciplinary and multi-dimensional understanding of women's experiences of living with RA, MS, and lupus. It names disenfranchised losses often related to these chronic conditions and makes constructive theological claims about the experiences and needs of women with autoimmune diseases. The dissertation underscores the need for caregiver reflection on the ways in which people understand illness and disability as a critical component of holistic and patient-centered care. Finally, the dissertation develops an intercultural and feminist model of spiritual direction to address the unique long-term psychospiritual needs of women with RA, MS, and lupus.

## **Chapter Two: Thick Description, Disenfranchised Losses, and Spiritual Struggles**

This chapter describes the experience of living with an autoimmune disease. It highlights the ways women—who make up the majority of people afflicted with autoimmune disorders—experience these conditions. I survey medical and psychological literature on rheumatoid arthritis, multiple sclerosis, systemic lupus erythematosus, and chronic illness in general to develop a portrayal that includes medically-oriented descriptions of the diseases, as well as common illness experiences (delayed diagnosis, pain, fatigue, depression, and liminality). In this chapter, I also name and depict potential categories of disenfranchised or unacknowledged losses associated with a woman’s experience of autoimmune disorder (identity, relationships, self-agency, and spiritual losses). Attention to unacknowledged losses is critical to the development of practical caregiving approaches—such as a model of spiritual direction—that can help women who have RA, MS, and lupus sustain well-being over time. The chapter concludes by addressing the relationships among spiritual struggles, health, and well-being.

Throughout this chapter and in Chapter Three, I include quotes from people who have RA, MS, or lupus. I identify the author of each quote as either “a woman with . . .” or “a person with . . . ,” depending on the source material. Although my preference was to use quotes from women, I worked with the available material to develop a representative portrayal of life with these autoimmune diseases. I use these quotes to underscore the

importance of acknowledging the oft-disenfranchised lived experiences of RA, MS, and lupus.

The quotes are set apart, centered, and highlighted in italics. This variation in text facilitates the reader's experience of shifting between two perspectives: descriptions of life with autoimmune disease and material that analyzes and comments on such experiences. Readers may find this shifting process unsettling, and that is intentional. As I will describe, women with RA, MS, and lupus frequently shift between wellness-in-the-foreground and illness-in-the-foreground perspectives on their experiences. The literary shifts in this dissertation echo a woman's experiences of vacillating between times when she is only able to cope with the immediacy of lived experience (illness-in-the-foreground) and times when she is better able to reflect on her experiences and make meaning of them (wellness-in-the-foreground). Although the literary shifts are a weak approximation of the more profound perspectival shifts of living with an autoimmune condition, they illustrate how energy and attention are required to repeatedly negotiate such changes.

As noted in Chapter One, this dissertation focuses on RA, MS, and lupus because their physical profiles are so similar (i.e., they are incurable diseases of unknown origin that typically manifest in chronic pain, fatigue, and malaise). These similarities suggest that women with these conditions may also share similar disease-related psychological and spiritual experiences, at least to the degree that general conclusions can be drawn about potential experiences of disenfranchised losses and spiritual struggles. Looking at descriptions of shared illness experiences also helps develop a thicker description of the



role of spirituality in the lived reality of chronic illness, and it helps overcome disadvantages associated with focusing on one disease (Ironside et al., 2003, pp. 172-173; see also Pattison, 1989, p. 16).

I recognize that any description is incomplete inasmuch as it cannot include all possible variations and nuances of any particular individual's experience. Many factors, such as diverse dimensions of social identity (e.g., race, culture, sexual orientation, religious affiliation, and socioeconomic status), contribute to the contextual nature of lived experience. However, the intent of this chapter is to highlight common dimensions of the autoimmune illness experience that may precipitate disenfranchised losses and spiritual struggles. Identifying commonalities across women's experiences of RA, MS, and lupus is useful to the degree that it highlights life-limiting aspects of chronic illness. This perspective does not diminish the importance of an intercultural approach to care where caregivers attend to the distinctive ways each woman lives with her illness. A tension exists between caregiver awareness of potential struggles and losses that may be shared by women with autoimmune diseases and the reality of an individual woman's highly contextual experience with her condition. In this sense, the experience of autoimmune disease is as idiosyncratic as the experience of spirituality.

Attention to disenfranchised losses and spiritual struggle, which may be perceived solely as life-limiting dimensions of illness, will be balanced in Chapter Five with a corresponding focus on life-enhancing spiritual growth and transformation, meaning-making, coping strategies, and spiritual practices. Researchers looking at chronic illness have attended primarily to either negative (e.g., in the 1980s) or positive

(e.g., in the 1990s) dimensions of the experience (Thorne & Paterson, 1998). When literature privileges life-enhancing outcomes of chronic illness over challenges and losses, it unintentionally contributes toward experiences of disenfranchisement because women may feel implicitly judged for their struggles and losses and may then privatize these experiences. An overly positive focus reinforces the tendency for people who do not live with chronic and/or disabling conditions to idealize those who do live with these conditions.

Focusing primarily on negative experiences is also problematic. Negative characterizations diminish the full complexity and ambiguity of the lived experience, such as the ways a person can experience well-being while living with an incurable disease (Thorne & Paterson, 1998, pp. 175-176; see also Stamm et al., 2008, p. 665). This dissertation seeks to holistically address autoimmune disease by acknowledging the ambiguous nature of living with the limits of a chronic illness—limits which have the potential to be both life-enhancing and life-limiting.

### **Autoimmune Diseases**

*Autoimmune disease* broadly refers to a group of conditions where the immune system, designed to protect the body against invasion by foreign entities, attacks the body itself. Autoimmune disease was once considered a myth. In the early 1900s, German immunologist Pau Ehrlich coined the term *horror autotoxicus* to refer to the implausible idea that an individual's immune system would attack its own body (Nakazawa, 2010, pp. 35-36). Autoimmune diseases have only been recognized as viable physical disorders

since the middle of the twentieth century ("Definition of autoimmune disease," 2008), although they are not yet formally accepted as a scientific category of disease ("Autoimmune disease in women," 2010).<sup>1</sup> The historical reluctance to acknowledge autoimmune disease contributes toward women's experiences of delayed diagnosis and disenfranchised losses.

For unknown reasons, the vast majority—nearly 75 percent—of people who have autoimmune diseases are women (D. K. Cassell & Rose, 2003, p. viii). Female to male ratios for the diseases of interest in this dissertation are: 2.5 to 1 for rheumatoid arthritis, 2 to 1 for multiple sclerosis, and 9 to 1 for lupus ("Autoimmune disease in women," 2010). Autoimmune diseases are one of the “top ten leading causes of all deaths among U.S. women age 65 and younger. Moreover, these diseases represent the fourth largest cause of disability among women in the United States” ("Autoimmune disease in women," 2010).

I develop a thick description of life with RA, MS, and lupus by first briefly describing each condition individually from a medical, disease-oriented perspective. Then I elaborate on the physical and psychospiritual illness experiences of these diseases in aggregate.

### **Disease perspective: Rheumatoid arthritis.**

*I don't walk as quickly across the parking lot,  
so I have to get up earlier if I need to be somewhere.*

---

<sup>1</sup> A widely accepted definition of *autoimmune disease* is still evolving within the medical community. Today, over 80 diseases are generally considered to be autoimmune disorders, including RA, MS, and lupus ("Autoimmune disease in women," 2010).

*My fingers just don't work like they should. I have to have help with zippers and buttons.*

*So I have to plan for how long that will take.*

*My hands can be so sore and weak that I can't hold onto a doorknob to open a door  
and get through. I have to use my shoulder and wedge my way in.*

*To push a vacuum cleaner, that shouldn't bother you.*

*It shouldn't bother a normal human being.*

*But when you have arthritis, all the normal things that you used to do  
without even thinking about them become a task.*

(A woman with RA, quoted in Plach, Stevens, & Moss, 2004a, p. 143)

Rheumatoid arthritis takes two forms: the more common adult-onset RA, which affects all ethnic groups between the ages of 30 and 50, and juvenile RA, which strikes children (D. K. Cassell & Rose, 2003, p. 196; "Who gets rheumatoid arthritis?," 2007). Following nearly 40 years of declining numbers, a recent Mayo Clinic report indicates that diagnoses of RA have increased since 1995 ("Increasing incidence of rheumatoid arthritis in women," 2008). Although researchers continue to pursue several theories, no one knows for certain what causes RA. With rheumatoid arthritis, the body's immune system attacks the lining of the joints, the synovium, as if it were a foreign entity. Although RA is primarily associated with the joints, all connective tissue is at risk, including tissue in the eyes, lungs, and heart ("What is rheumatoid arthritis?," 2010). Common symptoms include intense joint pain, stiffness in the morning and after periods of inactivity, joint swelling and redness, fatigue, mild fevers, and general achiness. These

symptoms may remain relatively constant, or they may appear in force during “flares” that are buffered by periods of remission.

When the disease is active, RA can render a woman unable to perform any number of daily tasks, such as dressing herself or brushing her teeth. Rheumatoid arthritis is the most functionally limiting musculoskeletal disorder, and the majority of people with the disease stop “employment within 10 years of disease onset” (Young, 1992, p. 620). Without adequate medical treatment, this difficult to control degenerative disease causes permanent joint damage, eventually leading to immobility and disfigurement (D. K. Cassell & Rose, 2003, p. 196). Women who have RA can anticipate a life expectancy shortened by approximately three years relative to women who do not have the disease (Matsumoto, 2010).

**Disease perspective: Multiple sclerosis.**

*I think the best way I can describe to people what MS is like for me  
is that I wake up every morning of my life feeling like I've got the flu.*

*So you really don't want to do anything, but you have to push through that barrier*

*and do it anyway or else you would never do anything*

*because your first inclination is to go back to bed and lay around all day*

*like you've got the flu . . . but tomorrow is going to be exactly the same.*

(A person with MS, quoted in Douglas, Windsor, & Wollin, 2008, p. 161)

Multiple sclerosis is a degenerative, often invisible disease in which the body's immune system attacks the protective myelin coating of nerve cells in the brain and along the spinal column (McNulty, 2007, p. 290). The resulting scar tissue impedes proper nerve functioning. The disease progresses in one of three typical patterns: (1) relapsing-remitting multiple sclerosis (the disease exacerbates and abates; 65–70 percent of patients display this pattern), (2) progressive MS (continuous decline; affects 15–20 percent of patients), and (3) benign MS (the disease is inactive; affects 10-20 percent of patients) (McNulty, 2007, pp. 291-292; see also Keegan & Noseworthy, 2002, p. 288).

Over time, approximately 75 percent of people who have multiple sclerosis experience disabling conditions because of the disease (Compston & Coles, 2002, p. 1224). These conditions may include cognitive processing issues, problems speaking clearly, fatigue, vision problems (including loss of sight), muscle weakness, loss of muscle control, coordination and balance problems, “pins and needles” feelings in the extremities, incontinence, sexual dysfunction, and pain (Barrett, 1995, p. 159; Fong, Finlayson, & Peacock, 2006; Irvine, 2009, p. 599). Pain has been an unacknowledged consequence of MS because medical practitioners incorrectly assumed for years that this was a painless disease. However, there are many people with multiple sclerosis who confirm that “persistent pain of moderate-to-severe intensity” is part of their everyday experience (Douglas et al., 2008, pp. 159, 165). Cognitive issues (e.g., memory loss, inability to focus, and diminished reasoning processes) affect as many as 50 percent of people with multiple sclerosis (McNulty, 2007, pp. 290-291). Cognitive degeneration and

fatigue are the most frequently cited reasons for the high unemployment rate of people who have MS (Irvine, 2009, p. 604).

Multiple sclerosis typically appears in the prime of life, between the ages of 25 and 50 (Irvine, 2009, p. 599; Russell, White, & White, 2006, p. 66), although five percent of people are diagnosed before age 16 (Compston & Coles, 2002, p. 1224). In addition to targeting women, MS is also nearly twice as prevalent in Caucasians compared to other ethnic groups (D. K. Cassell & Rose, 2003, p. 7). The disease rarely affects people of Asian or African descent (McNulty, 2007, p. 289). MS also occurs more frequently in cooler climates (D. K. Cassell & Rose, 2003, p. 45). In spite of neurological complications, people with MS typically have an average lifespan (DiLorenzo, Becker-Feigeles, Halper, & Picone, 2008, p. 1088).

**Disease perspective: Systemic lupus erythematosus.**

*One of my boys was so devastated by the physical changes in me  
that he tried to kill himself by huffing gas  
because to him I have become a totally different person.*

(A woman with lupus, quoted in Miles, 2009, p. 7)

Another autoimmune disease that disproportionately affects women is systemic lupus erythematosus. This disease is twice as likely to affect women of color (Giffords, 2003, p. 58), and mortality rates in African American women are thrice those of Caucasian women (D. K. Cassell & Rose, 2003, p. 7). The disease can appear at any

time, but typically occurs between 15 and 45 years of age (D. K. Cassell & Rose, 2003, p. 224). Mayo clinic records indicate that lupus diagnoses have tripled in the United States within the past four decades (Uramoto, 1999, p. 43).

When a person has lupus, the immune system attacks organs and tissues within her body. Symptoms include pain, fatigue, fever, hair loss, joint inflammation (mimicking RA), sun sensitivity, mouth or nasal ulcers, blood and kidney disorders, and body rashes, including a characteristic butterfly-shaped rash on the person's face (Giffords, 2003, p. 60). Chronic joint pain is one of the most common complaints, reported by 85 percent of patients. The destruction to a person's body may eventuate in kidney failure, heart disease, or life-threatening infection ("Prognosis and a hopeful future," 2010), but the vast majority of people with lupus have a normal life span ("Prognosis and a hopeful future," 2010). Like RA and MS, lupus presents in one of three states: symptomatic "flares," chronic disease activity, and periods of remission (Moses, Wiggers, & Nicholas, 2008, p. 868).

**Shared illness experience: Delayed diagnosis.**

*Well, if the doctor can't cure you he's not interested in you really.*

(A person with MS, quoted in Douglas et al., 2008, p. 163)

Autoimmune disorders are notoriously difficult to diagnose, requiring "an average of seven years and five doctors" to confirm their authenticity (D. K. Cassell & Rose, 2003, p. xvi). The lengthy diagnostic period exists in part because RA, MS, and lupus



resemble each other—and many other conditions—in the general litany of symptoms that patients typically present to their health care providers. Medical professionals readily attribute muscle pain, joint pain, low-grade fever, and fatigue to a number of medical maladies that range from relatively short-lived and insignificant conditions to chronic and life-threatening diseases.

A second factor in delayed diagnosis is that symptoms for these conditions often appear randomly. A woman with an autoimmune condition may feel pain in her shoulder today, but tomorrow the pain will be located in her knee, or her balance may be off one day and normal the next. As a result of random disease activity, women may delay seeking care until symptoms, such as debilitating pain and fatigue, settle in for longer periods or render her dysfunctional. The random nature of autoimmune symptomatology also means that although a woman can be bedridden one day, by the time she is able to see a health care provider for physical examination she may feel normal again, causing both parties to doubt the reality of a physiological cause for her complaints.

Adding to the elusive quality of autoimmune symptoms is the fact that diagnosis of RA, MS, and lupus requires patterns of symptoms or the appearance of a number of diagnostic markers rather than reliance on definitive medical tests (e.g., "Lupus: Frequently asked questions," 2010). Equally vexing to women seeking diagnosis is the invisible nature of these diseases. The paradoxical fact that most women with autoimmune conditions look healthy most or all of the time exacerbates frustrations of delayed diagnosis. For some women, "youth and beauty render an invisible illness even more invisible," making it impossible to "enforce her identity claims as ill as long as she

appear[s] healthy, pretty, and able” (Charmaz, 1995, pp. 665-666). My own diagnostic process took a relatively brief seven months before a blood test finally tipped the scales in favor of rheumatoid arthritis. I was lucky; many women endure years of uncertainly, uncomfortable or frightening diagnostic medical procedures, and patronizing attitudes from family, friends, and health care providers before a conclusive medical diagnosis validates the reality of their condition.

These imperfect diagnostic methods and the long-held belief that *horror autotoxicus* was physically impossible undoubtedly contribute to the fact that as many as “65 percent of patients diagnosed with autoimmune disease have been labeled hypochondriacs in the earliest stages of their illnesses” (D. K. Cassell & Rose, 2003, p. 32; see also "Autoimmune disease in women," 2010). These factors also contribute to disenfranchised losses and spiritual struggles as a woman with RA, MS, or lupus spends months, if not years, battling an unidentified enemy whose reality is suspect, even to her. As she seeks solace within her spiritual world-making, she may find that her spirituality lacks the breadth or depth necessary to provide lasting comfort in the face of repeated, unexplained suffering.

Delayed diagnosis also foreshadows the liminal nature of chronic illness that becomes evident over time. In the pre-diagnosis stage, each day may bring a unique experience of the disease through a completely different constellation of aches, pain, fatigue, and energy. The ever-changing physical reality of uncontrolled autoimmune disease prompts feelings of uncertainty about a woman’s bodily sensations, her ability to

convince others—particularly medical experts—of her condition, and her ability to make sense of what is happening to her within the greater context of her life.

**Shared illness experiences: Pain, fatigue, and depression.**

*You know it's chronic total constant pain and it affects your personality,*

*becoming inward . . . down . . . depressive.*

(A person with MS, quoted in Douglas et al., 2008, p. 160)

Chronic pain can permeate a woman's life when she has an autoimmune disease. Simply responding to her pain in the present moment is insufficient. With chronic pain, a woman must also consider the potential severity of pain she may feel in the near and distant future as she plans for big events as well as simple everyday activities, such as grocery shopping. The need for constant pain prediction and management affects her quality of life, particularly the sense of control she feels she has over it (Finan, Zautra, & Tennen, 2008, p. 552).

When pain becomes chronic, it “fundamentally alters the entire experience” (Hilbert, 1984, p. 367). For example, understandings of acute pain as a positive, protective physiological mechanism fail to account for chronic pain that takes on moral connotations of punishment over time (E. J. Cassell, 2004/1991, p. 267; see also Hilbert, 1984, p. 369; Underwood, 2006, p. 5). In fact, pain challenges meaning on many levels:

At the body level, patients feel that the pain is invasive and destructive. At the level of self, pain causes disintegration and decentering . . . at the level of social relationships the pain is disruptive and consequently isolating; and at the level of the lived-in cosmos, the pain is a problem of evil—a theodicy—and therefore a

disruption of meaning and good order. At every level pain breaks the order of things, becomes a foreground phenomenon, and shatters the rest. (Glucklich, 2001, p. 76)

Just as pain may be triggered by physical, psychological, social, and spiritual catalysts, “intense pain can exacerbate psychological distress, disrupt social relationships, and intensify spiritual alienation” (Doka, 2009, p. 33).

*The fatigue, it's hard to explain. . . . It's not your coffee or tea type of fatigue.*

*You feel like you just can't move. It's like getting by on 2 hours of sleep a night forever.*

*It's like swimming underwater in slow motion.*

*You can see the energy everyone else is having*

*and you're trying to keep up, but you're so tired.*

*You're walking in quicksand, and everyone else is hopping and jumping.*

(A woman with RA, quoted in Plach et al., 2004a, p. 145)

It is difficult for women to communicate to others how the pervasive fatigue of RA, MS, and lupus differs from everyday tiredness (Pettersson, Möller, Svenungsson, Gunnarsson, & Henriksson, 2010, p. 1939). As the preceding quote from a woman with RA describes, fatigue affects everything a woman does—or tries to do. In fact, fatigue can be more challenging to cope with than pain. I have learned to ignore low-to-moderate levels of rheumatoid arthritis pain, responding only to pain severe enough to break through everyday consciousness. For the most part, my RA-related pain is associated with a limited number of joints at any given time. Fatigue, on the other hand, is systemic, and this fact alone makes it much more difficult to ignore or “work around.”

Other women with autoimmune diseases share these sentiments about fatigue. Lupus patients portray fatigue as so “overwhelming” that it “dominates and controls most situations in life” (Pettersson et al., 2010, p. 1935). People who have RA indicate that fatigue has a profound effect on their ability to function, regardless of perceived pain level (Parrish, Zautra, & Davis, 2008, p. 701), and MS patients affirm that fatigue is a pervasive part of their illness experience (Irvine, 2009, p. 604).

The relationship between pain and fatigue is complex, and researchers concerned with chronic illnesses continue to explore how one symptom may exacerbate the other (Fishbain, Hall, Risser, & Gonzales, 2009). Studies indicate that some autoimmune-related fatigue may be a consequence of women coping with chronic pain, stress, and depression related to their conditions (Parrish et al., 2008, p. 694). The crushing effects of pain and fatigue can present formidable barriers for women to live “normal” lives and pursue their dreams.

*Oh yes, you can begin to think I wish I wasn't here.*

*And if it gets any worse you can become suicidal.*

(A person with MS, quoted in Douglas et al., 2008, p. 162)

*Been there, done that . . . it ain't easy. . . .*

*If I made a list of the things I used to do it would be far too depressing.*

(A woman with lupus, quoted in Miles, 2009, p. 6)

Another common experience of autoimmune disease is depression, which affects 27 to 47 percent of women with MS (Pakenham & Cox, 2009, p. 374) and 13 to 42 percent of people who have RA (Margaretten et al., 2009, p. 1586). Over 50 percent of people with lupus have psychological struggles and depressive symptoms as a result of their disease (Giffords, 2003, p. 64; Philip, Lindner, & Lederman, 2009, p. 575).

There are a number of reasons for the high incidence of depression and other mental health issues associated with autoimmune diseases, beginning with the significant impact that chronic illness has on lifestyle (e.g., Duval, 1984, p. 636; Eklund & MacDonald, 1991, p. 282). Other contributing factors include the unpredictability of the diseases (Giffords, 2003, p. 64; McNulty, 2007, p. 291); the level of disease activity (Margaretten et al., 2009, p. 1589); physiological changes in the brain (Giffords, 2003, p. 65; McNulty, 2007, p. 291); side effects of medications (particularly steroids, which are often used to help women cope with flares) (Giffords, 2003, p. 65); disability (Margaretten et al., 2009, p. 1589); changes in a woman's appearance (Giffords, 2003, p. 65); chronic pain (Giffords, 2003, p. 66); post-traumatic stress disorder-like symptoms related to a bleak prospective future of degenerating illness (Russell et al., 2006, p. 66); meaning-making in which the illness is perceived as "catastrophic and uncontrollable" (R. C. Katz, Flasher, Cacciapaglia, & Nelson, 2001, p. 561), and losses (Keefe et al., 2002, p. 643).

The effects of autoimmune disease are so emotionally wearing that one study found that "cancer patients were less demoralized by their illness and reported more benefits from it than did patients with lupus. Cancer patients were also less emotionally

distressed and reported less pain” (R. C. Katz et al., 2001, p. 570). This difference in psychological impact may be due to many factors (e.g., the incurable nature of lupus relative to “cancer survivors” who now experience more hope for their future, or enhanced levels of social support for people with cancer, a disease with greater public awareness and support), but the difference is nevertheless notable.

Depression is another dimension of chronic illness that is often neglected, perhaps because people assume “that those with a chronic illness have an understandable reason for ‘feeling down’” (Giffords, 2003, p. 66). Depression may also be disenfranchised because it affects more women with chronic illnesses—particularly women in lower economic groups—than men with chronic illnesses (O’Neill & Morrow, 2001, p. 264; see also Steck, Amsler, Kappos, & Bürgin, 2000, p. 19).

Experiences of chronic pain, chronic fatigue, and depression can create isolating barriers between the affected person and the outside world. Not only do these experiences make it more difficult to physically engage with others or participate in meaningful activities—including spiritual practices—these experiences also encumber a person psychologically (e.g., fatigue heightens experiences of stress) and spiritually (e.g., prompting questions of meaning, such as Why me?).

**Shared illness experience: Liminality.**

*Often, I can be in significant pain but appear fine,  
or I can feel fine and be close to kidney failure.*

(Laura, a woman with lupus, quoted in Maggio, 2007, p. 577)

*What [I] used to be is not there anymore. I have to find a new way of describing myself.*

*I can't say I'm healthy anymore. I have to find a new word.*

*I have to find a whole new way of looking at myself.*

(Julia, a woman with MS, quoted in Ironside et al., 2003, p. 178)

Regardless of the levels of pain and fatigue a woman experiences, the pharmaceutical regimen she follows, or the impact it has on her daily life, autoimmune disease is always a *liminal* experience. Liminality is a place of betwixt and between, a place where a woman is neither healthy nor sick, and at the same time, she is both healthy and sick (Alsaker, Bongaardt, & Josephsson, 2009, p. 1159; Doka, 2009, p. 169; Wendell, 1996, p. 3). The liminal state has been described as a place of “volatility” (Miles, 2009, p. 8) and a perpetual “at-risk” position (Loveys, 1990). For this dissertation, Paterson’s (2001) “shifting perspectives” provides a helpful way of understanding the liminal nature of autoimmune disease.

Two terms will be used throughout this dissertation to describe the lived experience of autoimmune disease: *illness-in-the-foreground* and *wellness-in-the-foreground*. *Illness-in-the-foreground* is “characterized by a focus on the sickness, suffering, loss, and burden associated with living with a chronic illness; the chronic illness is viewed as destructive to self and others” (Paterson, 2001, p. 23). *Wellness-in-the-foreground* describes

chronic illness as an opportunity for meaningful change in relationships with the environment and others. The person attempts to create consonance between self-identity and the identity that is shaped by the disease, the construction of the illness by others, and by life events . . . [T]he self, not the diseased body, becomes the source of identity. (Paterson, 2001, p. 23)



Ongoing experiences of loss associated with autoimmune diseases can threaten a wellness-in-the-foreground perspective, either by causing a shift to an illness-in-the-foreground perspective or, “if expressions of grief or loss are seen as antithetical to the wellness in the foreground perspective, [women] may be reluctant to address their loss or suffering” (Paterson, 2001, p. 25). These unacknowledged—or disenfranchised—losses contribute to chronic psychospiritual struggles.

The different perspectives of wellness-in-the-foreground and illness-in-the-foreground may have interconnected worldviews, self-understandings, and even theologies of self, suffering, and God/the transcendent. For some women, the shifting perspectives of their experiences with autoimmune diseases are analogous to moving back and forth between two realities or worlds. People cope with the stress of chronic illness by integrating experiences into their perspectives (conserving existing ways of thinking), transforming perspectives to accommodate new experiences, or a combination on these processes (e.g., McIntosh, 1997, p. 178). I will explore the shifting perspectives of chronic illness in Chapter Five in relation to healing rituals that may help women with RA, MS, and lupus effectively negotiate these transitions in life-enhancing ways.

As women struggle with the liminal reality of autoimmune disease, they may “resist ‘owning’ the disease by avoiding referents such as ‘my’ illness. Others may allow their identity to become subsumed by the disease” (Keck, 2002, p. 214; see also Reynolds & Prior, 2003, p. 1234). Some women recognize that there are times when it is beneficial to stand firmly on one side or the other of the line that separates *sick* from *healthy*. For example, when the illness is in sharper focus, a woman may receive needed medical care,

whereas “distancing from the sickness allows for a focus on emotional, spiritual, and social aspects of life” (Paterson, 2001, pp. 24-25). Regardless of where she stands at the moment, her position is always tenuous, and this sense of perpetual uncertainty can lead to or exacerbate spiritual struggles about who she is and how she is in relationship with God/the transcendent.

### **Disenfranchised Losses Associated with RA, MS, and Lupus**

*What worries me is that there are so many days when I find one more thing that I can't do. It bothers me that I can't pick up the milk carton like I used to or I can't bend down to see what's under the bed. . . .*

*Then I think, “Oh, my God! I can't do that now. That's one more thing.”*

(A woman with RA, quoted in Plach et al., 2004a, p. 144)

As traumatic as the initial diagnosis of an incurable disease may be, it is often the ongoing, everyday losses and long-term issues that most profoundly affect a person's illness experience (Ironsides et al., 2003, p. 173; Koenig & Cohen, 2002a, pp. 180-181; Lundman & Jansson, 2007, p. 113; McNulty, 2007, pp. 293-294). The flare/remission cycle typical of RA, MS, and lupus means that women with these diseases continually encounter physical setbacks as well as psychological and spiritual losses over the course of the illness. If women or members of their support community do not acknowledge these losses they become *disenfranchised*:

*Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected . . . Much of the*

experience of disability and illness goes underground, because there is no socially acceptable way of expressing it and having the physical and psychological experience acknowledged. (Wendell, 1996, p. 40)

Women who have RA, MS, and lupus; their families, friends, and social networks; and the cultural milieu in which they live may all explicitly and implicitly suppress expression and acknowledgement of losses associated with autoimmune conditions (Meagher, 1989, p. 315).

There are a number of reasons why people do not acknowledge losses related to RA, MS, and lupus. When the physical effects of chronic disease are invisible to others, it is easy to neglect losses (Boss & Couden, 2002, p. 1352; Vickers, 2000, p. 132). Members of a woman's support system may experience "compassion fatigue" and tire of listening to a litany of losses over time (E. J. Cassell, 2004/1991, p. 42). Members of the support system may assume that a woman will simply adjust to or accept new losses in time. Another reason disenfranchisement happens is that some people only associate grief or mourning with death or with illnesses that are imminently life-threatening, such as cancer (Thompson, 2002, p. 8).<sup>2</sup>

*Nobody goes through the emotions in the same order  
and sometimes you have to allow yourself to go back and go through  
one or more of the emotions again and again however long it takes  
for you to deal with it yourself . . . and to allow yourself the right to do that.*

---

<sup>2</sup> Often people use *life-threatening* as a synonym for *immanently fatal*. This understanding does not account for the multitude of ways chronic conditions can threaten a woman's life in terms of the quality of the lived experience. A more thorough discussion of these understandings and the ethical consequences of how we define *life-threatening* (e.g., exploring biomedical ethics surrounding end-of-life care) is beyond the scope of this dissertation.

*The right to be unhappy, the right to feel all the different things.*

*You need to learn about yourself. To listen to your body and to find the best ways for you to deal with the different situations because not everybody is the same.*

(A woman with MS, quoted in Reynolds & Prior, 2003, p. 1234)

Many losses associated with autoimmune disorders seem trivial—albeit still meaningful to the person who is experiencing them—relative to socially-sanctioned occasions for grief, such as death, public traumatic events, or diagnosis with a terminal disease (Sapey, 2004; Sullender, 1979, p. 245; Wendell, 1996, p. 65). In general, chronic illness lacks cultural guidelines for what is and is not an “appropriate” loss or an “appropriate” expression of grief.<sup>3</sup> What constitutes an occasion for mourning differs within cultural groups, gender, and social class (Doka & Martin, 2002, pp. 339-340). The grieving process also varies by individual; some people are naturally more inclined to express their grief than others.

Women who express grief in less emotive ways “tend to be, at least in many Western societies, disenfranchised early in the grieving process, especially in the culture of counseling, where their lack of emotion is seen as detachment, denial, or repression,” and these women are also ultimately the most disenfranchised grievers (Doka & Martin, 2002, p. 342). More emotionally expressive, “intuitive grievers are more likely to be disenfranchised later in their grief process” (Doka & Martin, 2002, p. 342). Within the

---

<sup>3</sup> Pastoral theologians recognize that we lack cultural guidelines for grieving many common life experiences, including miscarriage and divorce. Some theologians are working to increase awareness of and develop rituals for such experiences (e.g., Anderson & Foley, 1998). Chronic illness, however, remains unnamed in this literature.

context of chronic illness, it is particularly important for caregivers to encourage broad understandings of loss and bear witness to grief for losses big and small.

Current literature on women's experiences of RA, MS, and lupus addresses losses that may occur with these illness experiences, but the literature does not specifically address the potential for disenfranchised loss. A review of the psychological literature published in recent decades reveals that only a few articles associate disenfranchised loss with chronic illness experiences (e.g., Devins & Seland, 1987; Sullender, 1979; Thompson, 2002). Psychological literature on disenfranchised losses has traditionally focused on death, although in 2002, Doka noted that following publication of his book *Disenfranchised Grief: Recognizing Hidden Sorrow*, "the concept has gained a conceptual life of its own. It has been applied to a range of losses wider than I initially considered" (p. xiv). While new contexts for grief have emerged (e.g., miscarriage, divorce), chronic illness remains neglected. However, as I will demonstrate, these bodies of literature contain a wealth of information to support my contention that women with autoimmune conditions experience disenfranchised losses associated with their identity, relationships, self-agency, and spiritual beliefs and practices.

### **Identity losses.**

*I had to cut my hair off, my hair used to be long . . . I couldn't manage it,  
so it has to be short, so it doesn't need blow drying  
because I can't get my arm above my head.  
Yeah this type of practical things take away some of your femininity,*

*or change who you are.*

(A woman with RA, quoted in Lempp, Scott, & Kingsley, 2006, p. 115)

Body and identity are inextricably linked, making illness and disability catalysts for identity transformations (Doka, 2009, p. 88; Irvine, 2009, p. 600). Changes to the body may affect a woman more than a man in cultures where a woman's appearance is highly valued, such as in the United States (Wendell, 1996, pp. 43-44; see also Stone, 1995, p. 420). For women who have autoimmune diseases, challenges to aspects of self-image and identity (e.g., sexual attractiveness and femininity) begin during the often lengthy diagnostic period or immediately thereafter, and they continue over the course of the disease (Irvine, 2009; Kralik, Brown, & Koch, 2001; Lempp et al., 2006).

*It is my hands, the shifting of the fingers. That's what made me start to feel arthritic.*

*For years, I could always keep them straight when I wanted to. Now, I can't.*

*Some things I can hide, like I can wear long dresses to hide knees  
and shoes to cover my toes. But you can't hide your hands.*

(A woman with RA, quoted in Plach et al., 2004a, p. 147)

*Good friends . . . actually see me before the wheelchair . . .*

*I find that some people see the wheelchair before me.*

(A woman with MS, quoted in Reynolds & Prior, 2003, p. 1237)

Pain, fatigue, physical limitations, and treatment regimens all bring new dimensions of bodily experience to the forefront of a woman's attention. Many women with RA, MS, and lupus feel betrayed by bodies they once took for granted (Charmaz, 1991, pp. 660-662; J. Katz, 2002; Kleinman, 1988, p. 180). As lupus, RA, and MS progress in degenerative fashion, women may face a number of appearance altering consequences related to the diseases and the medications used to treat them, including disfigured joints (particularly the hands of women who have rheumatoid arthritis); the need for assistive devices (e.g., cane, wheelchair, arm splints); "rashes, lesions, hyperpigmentation, or scarring" (90 percent of lupus patients experience these skin conditions); hair loss; and weight gain (Seawell & Danoff-Burg, 2005, p. 866; see also Giffords, 2003, p. 63).

Western culture continues to stigmatize visible signs of illness and disability in overt (e.g., through blatant discrimination) and covert ways (e.g., through the shame women feel about imperfect bodies) (Vickers, 2000, p. 137; also see Lempp et al., 2006, p. 115). When women display signs of sickness or disability, either temporarily or permanently, they are labeled by society (e.g., as a "diseased person," E. J. Cassell, 2004/1991, p. 49). Labels immediately challenge a woman's identity with self-imposed and/or externally-imposed moral judgments related to imperfect bodies, and she may experience spiritual struggles related to shame, sin, or karmic justice.

*It is ironic that one of my most salient personality characteristics is  
to be critical of myself and metaphorically to beat myself up*

*and that I have a disease in which my cells literally beat up my own cells!*

(Laura, a woman with lupus, quoted in Maggio, 2007, p. 577)

The “biographical disruption” of chronic illness (Bury, 1982) is even more pronounced when it is triggered by autoimmune disorders because these diseases are literally defined as the body attacking itself. People have characterized autoimmune diseases as “self-destruction” (Taïeb et al., 2010, p. 594) and “being allergic to yourself” (E. Cohen, 2004, p. 7). These and other negative images affect notions “of self as active, independent, providing for others and capable in employment” (Irvine, 2009, p. 600). In general, being identified as a sick person is a devaluing experience in Western society where “good health is considered ‘conformity’” (Mann, 1982, p. 3).

*The messages I received from my family were clear: Self-sacrifice and hard work are of the utmost importance. These messages also come from the larger cultural views of women as caretakers and nurturers as opposed to dependents.*

*For example, instead of acknowledging the fatigue that often accompanies lupus,*

*I am quick to view it as laziness or lack of motivation.*

*And besides, I do not look sick, so how can I be?*

(Laura, a woman with lupus, quoted in Maggio, 2007, p. 579)

The sick role is typically not detrimental to a person’s identity in the case of acute illness. In this circumstance, the ill person often readily accepts the sick role as it affords



her the opportunity to briefly relinquish normal responsibilities and recuperate. People in her support community are also relatively accepting of acute illness because they can reasonably expect the quick return of good health and familiar routine. In the case of chronic illness, however, acceptance of the sick role—in which “being sick is the primary obligation” (E. J. Cassell, 2004/1991, p. 258)—engages people in more complex and ambiguous ways.

*Let me tell you what I lost—I lost my profession. I loved it.*

*I was a beautician, and I can't even do my own hair today.*

*When I had to quit my job, I was already starting to lose my speed and my dexterity, and I was dropping things a lot. I was dropping my combs, dropping my brushes.*

(A woman with RA, quoted in Plach, Stevens, & Moss, 2004b, p. 39)

In the context of chronic illness, negotiating the sick role precipitates tensions between what a woman believes is expected of her and what she feels she can do. What a woman with RA, MS, or lupus “can” do is an inherently unstable condition qualified by the way the disease affects her at any given time and by instructions from health care professionals as to the type and level of activity likely to maintain or improve her disease state. For example, on a 95-degree day, a woman with MS may be physically capable of walking eight blocks from point A to point B. But if she does this, she risks a flare triggered by overheating (people with MS often do not respond well to exertion in high heat). If the woman is with an acquaintance who does not know she has MS, she must

reveal her illness to claim the sick role and exempt herself from the walk. She may not want to do this for a number of reasons (e.g., stigma, privacy). She could also lie in order to avoid the walk (e.g., telling her acquaintance she has a painful blister on her foot), but this option may result in moral distress and shame. This example illustrates how women with RA, MS, or lupus must frequently negotiate identification with the sick role, balancing the need for self-care with the desire to fulfill social expectations.

Even when she is too ill at any particular time to function as she wants to in the roles of wife, mother, homemaker, student, worker, professional, etc., a woman with RA, MS, or lupus often struggles to do so in order to maintain her independence and not become a burden to others (Charmaz, 1991, pp. 668-669; Fong et al., 2006, p. 700; Lempp et al., 2006, p. 112). This tension intensifies as these degenerative diseases increase her need to rely on others more over time (Plach et al., 2004a, p. 139). Social discourses about women's self-care, such as the belief that "good women . . . are supposed to give 'til it hurts; everyone is supposed to feel exhausted and overworked" (Wendell, 1996, p. 4), contribute to a woman's loss of identity as a capable, independent person.

Identity confusion and loss are exacerbated by ambiguous and judgmental expectations from a woman's support community, whose messages might be perceived as:

Be independent, not passive and dependent, and be active in your care; *but* when you have a serious exacerbation, place yourself submissively in our hands, and we will blame you for what you did or failed to do to worsen your disorder. (Kleinman, 1988, p. 170, emphasis in original; see also E. J. Cassell, 2004/1991, pp. 51-52)

Messages such as these make it even more difficult for a woman with a chronic health condition to maintain a stable identity on the healthy-sick continuum. Because these kinds of internal and relational dynamics are complex and difficult to describe, they are often privatized.

*I mean I worked for nearly 40 years, there is a certain loss of identity when you can't work anymore . . . When you can't work, not only have you taken away your sort of daily structure, you have taken away a large part of your social life.*

(A woman with RA, quoted in Lempp et al., 2006, p. 115)

The fact that most women are stricken with RA, MS, and lupus in the prime of their lives makes it even more difficult for them to maintain identities in many arenas (e.g., home, work, social networks). As noted, pain and fatigue cause many women to stop working outside of the home or lead to reduced levels of productivity in the workplace. Other losses associated with employment include fewer opportunities for advancement and diminished respect because people labeled as sick or disabled “are usually perceived as less able than healthy persons” to handle challenging job assignments (Barrett, 1995, p. 161).

*It is hard when you're young and you're diagnosed with an illness you know . . . I just want to be strong, I just want to carry on. I want to just live a normal life,*

*as normal as everybody else you know, that's it.*

(A woman with RA, quoted in Lempp et al., 2006, p. 116)

Because women are highly valued in society for caring for others, any life change that threatens a woman's abilities as a caretaker can challenge her identity (Kayser & Sormanti, 2002, p. 11). The tendency for women to nurture others includes caring for spouses, parents, and other community members, but it primarily means that women are expected to be the chief caretakers for infants and children. RA, MS, and lupus most often strike during prime years for bearing and raising children. My son and daughter were one and three-years-old when I was diagnosed with rheumatoid arthritis, and I experienced feelings of loss related to the type of active parent I had planned to be with them. It is common for women with autoimmune diseases to experience loss of parenting plans and dreams because they are physically unable to parent in the same way after disease onset (D. K. Cassell & Rose, 2003, p. viii).

Some women strongly associate their identity as women with their ability to bear children. Because the drugs used to treat RA, MS, and lupus may also put a pregnancy or unborn child at risk of health complications (D. K. Cassell & Rose, 2003, pp. 177-178), women with these diseases may experience the significant loss of their dreams to have any or additional children. Autoimmune conditions may affect pregnancy in ways that make it a difficult choice for some women to bear children. For example, RA may go into remission during pregnancy, but lupus and MS tend to flare up during this time (Duval, 1984, p. 637), putting the woman in the position of choosing between pregnancy and

what may become months of uncontrolled symptoms. Furthermore, “women with disabilities are often made to feel that their choices related to reproduction and mothering are deviant or socially irresponsible (Carty, 1995; Corbin & Strauss, 1991; Smeltzer, 1994; Thorne, 1990)” (Thorne, McCormick, & Carty, 1997, p. 6). This attitude may extend to women with potentially disabling diseases such as RA, MS, and lupus because these women may be unable to fulfill parenting duties in socially acceptable ways, and there is the potential to pass on a genetic propensity for autoimmune disorders (although the hereditary nature of RA, MS, and lupus currently remains unclear). Women who believe child-bearing and child-rearing are their primary and divinely-ordained roles may particularly experience spiritual struggles related to pregnancy and parenting.

**Relationship losses.**

*Relationships I get very upset about. The word frustration is a really important one which occurs often . . . because of the slowness of the mobility.*

*There is a lot of frustration which can occur between people in a relationship and that is a big feature of my experience.*

(A woman with RA, quoted in Lempp et al., 2006, p. 113)

Disrupted relationships—with partners, family, friends, coworkers, and/or God/the transcendent—are a near universal experience for women with RA, MS, and lupus (E. J. Cassell, 2004/1991, p. 274; Fong et al., 2006, p. 700; Giffords, 2003, p. 66; P. Kelley, 1998, p. 202; Kleinman, 1988, pp. 49, 186; O'Neill & Morrow, 2001, p. 265;

Pargament, 2007, p. 112; Philip et al., 2009). In some cases, relationships are enhanced as a result of chronic illness experiences (Fong et al., 2006, p. 700; Irvine, 2009, p. 605), but often they are negatively affected. Relationship losses have a direct effect on a woman's sense of well-being (Kayser & Sormanti, 2002, p. 11).

*You don't overload your requests on people*

*cause you ask too much and you lose a friend . . .*

*If you don't make too many demands on people, you keep your friends longer.*

(Nora, a woman with MS, quoted in Fong et al., 2006, p. 702)

There are a number of ways in which RA, MS, or lupus affect relationships. Initial diagnosis and the many questions about a woman's prognosis can elicit "uneasiness, and in some cases fear" within a woman's support community (Barrett, 1995, p. 161). People "may be embarrassed, revolted, shocked, silenced, sorry; they may change the subject; they may withdraw . . . [because] disclosure of information regarding a disease is not an experience people are socialized to deal with" (Barrett, 1995, p. 161; see also Boss & Couden, 2002, p. 1353; E. J. Cassell, 2004/1991, p. 275; Giffords, 2003, p. 67). Although withdrawal may seem a rather benign reaction, withdrawal that eventuates in complete loss of relationship is as painful as a relationship severed in outright anger.

Even before I was diagnosed with RA, but was living with great pain and anxiety about the source of the pain and other symptoms, my best friend abandoned me. From the

moment I shared with our Bible study group what was happening to me and the concerns I had about the eventual diagnosis, my friend stopped speaking to me. In fact, she would not even look me in the eye. In this time of great need, I was devastated by her response to my illness. Today I recognize that my friend may have felt betrayed by a broken “relationship contract” that assumed two independent and healthy women would be able to fully participate in life together (Lyons & Sullivan, 1998, p. 140). Our contract, however, became null and void with the onset of RA. A woman experiencing this kind of response from a member of her support community might easily imagine that it was her fault (i.e., she had “too many” needs, she was “burdening” her friend, or she was dwelling too much on her illness) and not grieve the loss of relationship.

*It's so hard to book anything, because you never know how you'll feel that day,  
it's almost impossible not to let people down all the time.*

(A woman with lupus, quoted in Pettersson et al., 2010, p. 1938)

After a woman becomes ill with RA, MS, or lupus, family and friends may grieve the loss of the person they once knew. This is known as an ambiguous loss because the “person is there, but not as they once were” (Boss & Couden, 2002, p. 1352). For example, a woman once known for her spontaneity is diagnosed with MS. Now, when making plans with friends, she must consider her current and predicted energy levels and the need to accommodate medications that require refrigeration. As much as she wishes to be, she is no longer spontaneous. Other sources of tension that affect relationships

include caregiver fatigue (Boss & Couden, 2002, p. 1353); the need to renegotiate roles and responsibilities as the woman with RA, MS, or lupus experiences loss of functionality (Giffords, 2003, p. 67; Irvine, 2009, p. 603; Lyons & Sullivan, 1998, p. 140); competition between people as to who is sickest (Grytten & Mäseide, 2005, p. 238); and resentment from others that a woman may use her illness as a strategy “to gain attention, money, status, revenge, or to escape responsibility” (Mann, 1982, p. 10).

*With rheumatoid arthritis, there's just no avenue to let out your feelings.*

*It all just stays inside. It makes me lonely and isolated.*

*I isolated myself a lot from people.*

*I did not have the energy, and people didn't understand.*

*I stopped going out. I lost a lot of friends.*

(A woman with RA, quoted in Plach et al., 2004b, p. 40)

Some sense of isolation is inherent to the autoimmune illness experience given the subjective and idiosyncratic nature of chronic pain and fatigue that only the woman with the disease can fully know (Cole & Pargament, 1999a, pp. 400-402). Relationship loss is another precursor to feelings of aloneness for the woman with RA, MS, or lupus. In addition to relationship disruption within a woman's circle of family and friends, an inability to maintain employment may add another layer of social isolation (Reynolds & Prior, 2003, p. 1237). Even relationship changes that are ultimately more life-enhancing for the person can have negative secondary effects. For example, one woman with MS



gave up the drugging and the drinking . . . this was a dramatic change as all the people (many) that I spent most of my time with were involved in drugs or alcohol. I knew that I had to give up those people as they were part of a lifestyle I could not share. This added to my loneliness. (Barrett, 1995, p. 163)

Ironically, women who experience disenfranchised losses in other areas of their lives may “become disillusioned with and alienated from their community. . . . The loss of community that may occur as a consequence of disenfranchised grief fosters an abiding sense of loneliness and abandonment” (Kauffman, 1989, p. 29). These feelings may be exacerbated if a woman also feels a sense of abandonment by God or detachment from the transcendent.

*I think the fatigue probably does more to a relationship than the immobility.*

*Because sometimes I just don't have the energy to be in a relationship.*

*I just don't have the energy to listen to his concerns or deal with his emotions.*

*I get through the day. I don't have anything else to give.*

(A woman with RA, quoted in Plach et al., 2004b, pp. 38-39)

*Sex, what's that word?*

(A person with MS, quoted in Douglas et al., 2008, p. 162)

Another significant area for potential disenfranchised grief is the loss of physical and sexual intimacy (e.g., Druley, Stephens, & Coyne, 1997, p. 512; Irvine, 2009, p. 605; Lempp et al., 2006, p. 113). Disease-related changes to a woman's appearance cause some women to avoid intimacy with their partners, particularly during disease flares

when symptoms are aggravated (Seawell & Danoff-Burg, 2005, p. 872). Some women may also find that “physical pain makes even loving touches unbearable” (Muldoon & King, 1991, p. 104). Although this may sound extreme, I have experienced times when even the weight of a bed sheet on my body resulted in excruciating pain. Loss of sexual intimacy may in turn exacerbate identity and relationship losses related to partner expectations that can no longer be met—at least not as they once were (Bediako & Friend, 2004, p. 203).

Given the challenges that many couples experience in negotiating changes in physical and sexual intimacy without the added burden of a chronic physical condition, it is not surprising that couples where one or both partners has an autoimmune disease would not have the communication skills or emotional intimacy to talk about or negotiate sexual needs. Although one might expect that lesbian couples find it easier to negotiate these issues because partners have the advantage of being socialized as women and might be supported by communities of women, such assumptions may be based more on stereotypes of women as nurturers than on research.<sup>4</sup> If heterosexual and lesbian couples in committed relationships have these challenges, single women who still want to experience physical and sexual intimacy in dating relationships are additionally burdened by questions of how and when to tell a date about one’s illness and concerns about negotiating sexual situations when she lacks energy or experiences too much pain for physical intimacy.

---

<sup>4</sup> Although research on the topic is scarce, Worth, Reid, and McMillan (2002), for example, suggest that women in lesbian relationships experience similar difficulties to heterosexual women when it comes to addressing sexual intimacy.

**Loss of self-agency.**

*A lot of doctors I find are very arrogant. They think they are God  
and that you should listen to them like they are and I'm just not prepared to do that.*

*A lot of doctors do not listen or they don't hear or they don't understand,  
or they assume they know what you are saying when they don't.*

(A woman with a chronic illness, quoted in Tang & Anderson, 1999, p. 90)

The biomedical model that dominates health care in the United States holds a great deal of power over people's ability to get the type of care they need. The strong explanatory power of the biomedical model and continued seemingly miraculous advances in medicine and medical technology afford biomedicine the irreproachable regard of a near religion "constructed around ritual practices, ethics, faith, symbol systems, and a sacred hierarchy of authority from patients, to nursing staff, to physicians" (Crawford, 2006, p. 32). This religion-like status extends to idolization of doctors as gods and perpetuation of the belief "that there is nothing that human beings suffer from that is not, in principle, subject to elimination by medicine" (Hanson, 1999, p. 179).

Although modern medicine relieves a great deal of human suffering, the shadow side of biomedical care is its tendency to dehumanize the very people who seek its help. Physicians in particular yield tremendous power over patients, and other health care professionals contribute to dehumanizing dimensions of medical care.<sup>5</sup> In health care

---

<sup>5</sup> Recent studies show that physician gender affects interactions with patients. Generally speaking, female physicians spend more time with each patient, are more collaborative, engage in more psychosocial counseling and questioning, use more positive and emotionally-focused talk, and elicit more psychosocial

relationships, the medical professional holds so much authority that patients' own experiences of their bodies are often discounted or outright denied—or disenfranchised in the language of this dissertation. As Tang (1999) puts it:

With chronic illness comes the definition of self as “patient” and the culture of patienthood that situates “the patient” in relation to healthcare providers as knowers and experts on the patient’s body. The body known, the body lived with, becomes estranged, as we rely upon the experts to interpret for us the workings of our own bodies, and biomedical tests to dictate the parameters of everyday activities hitherto taken for granted: what to eat, what to drink, when to eat, etc. . . . In chronic illness, the patient’s loss of autonomy, and the medicalization of the body, is not a temporary phenomenon, but is part and parcel of the everyday. (pp. 84, 86)

*I am separate from my body; my “medicalized” body,  
controlled by the experts, has become my enemy.*

(A woman with a chronic illness, quoted in Tang & Anderson, 1999, p. 84)

Loss of patient self-agency results in “consequences [that] are compounded for people who have little cognitive or social authority of their own, and for people who are routinely treated as though they are without such authority, such as *most women*” (Wendell, 1996, p. 119, emphasis added). For example, the medical establishment complicates the ability of women (and other people with little authority in the system) to get the help they need by paying little attention to conditions that primarily affect this population:

when diseases that are most prevalent in women, such as multiple sclerosis, rheumatoid arthritis, and systemic lupus erythematosus are considered, the

---

and biomedical information from their patients than do male physicians (Levinson & Lurie, 2004; Roter & Hall, 2004).

realities of daily living as a worker, mother, partner, and housekeeper are rarely addressed. It is also apparent that chronic conditions that occur predominantly in women take much longer to enter the mainstream of discussion in the medical literature (Senecal, 1990). (Thorne et al., 1997, p. 6)

Additionally, medical professionals' lack of attention to the full lived-reality of chronic conditions such as RA, MS, and lupus often results in care and treatment that are inadequate or inappropriate (E. J. Cassell, 2004/1991, p. 261; Kralik, 2002, p. 146; Thorne et al., 1997, p. 8).

*Cora described how she stopped seeking medical help after an experience:*

*One doctor who was really snotty said, "Does anyone else in your family have MS?" I said, "Yes". He said, "See, you just want to have MS and you want to be like her." . . . and that's the reason why I put it off and didn't fight.*

(Cora, a woman with MS, quoted in Fong et al., 2006, p. 702)

The potential breakdown of a woman's sense of self-agency begins before confirmation of the formal diagnosis of RA, MS, or lupus. As I have previously noted, autoimmune disorders are very challenging to diagnose, and medical caregivers often label women with autoimmune diseases as hypochondriacs in their medical records. In direct communications with patients, doctors may respond to a woman's complaints of pain and fatigue by telling her it is "all in your head" (Hilbert, 1984, p. 368), she is "worrying unnecessarily" (Kralik et al., 2001, p. 598), "others are 'much worse off,'" "You're imagining it," or "You're doing it to yourself" (Wendell, 1996, p. 126).

Historically, a diagnosis of *hysteria* was assigned to women who could not convince their physicians that their complaints were caused by identifiable biological disruptions (Glucklich, 2001, p. 197). Although hysteria is no longer a formal diagnostic category (Illis, 2002), skepticism remains for many women's complaints of indeterminate origin. Persistent doubt from medical caregivers (not to mention family and friends) causes women with RA, MS, and lupus to suspect their own sanity and the reality of the world as they perceive it (Becker, 1999, p. 37; Haugli, Strand, & Finset, 2004; Keck, 2002, p. 61; Kleinman, 1988, p. 57).

The inability to quickly identify and cure what ails a suffering patient can result in doctors having "feelings of anger, of inadequacy, and of being manipulated, which, in turn, can even lead to actively disliking certain patients" (Wasan, Wootton, & Jamison, 2005, p. 185; see also D. K. Cassell & Rose, 2003, p. 73). Such negative comments can destroy the doctor-patient trust relationship necessary for healing to occur, and a woman with RA, MS, or lupus may experience both loss of self-agency and the loss of an important caregiving relationship.

*With a badge, when you go and pull [the car] in disabled bays, people look at you.*

*You get comments: "She doesn't look disabled!" — laughing, you know.*

*But I just get out and carry on . . . My aunt chased a man once down the road in his car,*

*because he said: "You're not disabled"!*

*And she went: "You don't know she's not disabled,*

*you're not there of a night when she's in pain!" And he just drove off.*

(A woman with RA, quoted in Lempp et al., 2006, p. 115)

For some women, diagnosis of an autoimmune disease is a relief because it finally authenticates what they have been experiencing (Hilbert, 1984, p. 370; Kralik et al., 2001, p. 594; Tang & Anderson, 1999, p. 84). But, for many women, diagnosis simply presents different opportunities to defend themselves and their often invisible conditions, such as the situation described by the woman with RA (above) or women with MS who must confront accusations of drunkenness because of disease-related balance problems (Bury, 1991, p. 454; Reynolds & Prior, 2003, p. 1226).

*If you go to your doctor and they know you have MS*

*and you have something wrong with you they just put everything down to MS!*

(A person with MS, quoted in Douglas et al., 2008, p. 163)

Diagnosis does not always guarantee positive changes in a woman's relationship with the medical community. Even with a sanctioned diagnosis, women's reports of their lived experiences may still be discounted, much like experiences of pain with MS were once thought to be imagined. Research studies also negate illness experiences, such as fatigue associated with RA, even when these dimensions of illness are identified as important to study participants (Stamm et al., 2008, p. 658). For example, my rheumatologist privileges pain level and measures of functionality (e.g., a patient's ability

to get out of bed in the morning) over reports of fatigue level, even though I have repeatedly pointed out that fatigue presents greater challenges for me on a day-to-day basis, and other patients have shared with me that this is also true for them.

A recent post to members of the “Rheumatoid Arthritis Warrior” group on Facebook (September 19, 2010) posed the question: “Anyone out there feel ‘afraid’ to call the rheum doc about new symptoms or new joints affected?” Numerous responses included these representative comments:

*“Yeah sometimes, because all my rheumy wants to say is after I talk about all my complaints is ‘But you're doing better right?’ UM....NO if you would listen.”*

and

*“Wouldn’t do any good, he only hears what he wants to hear, and if you dont have the symptoms he says you are supposed to have, doesnt want to hear anything else, Wonder why I even go to him.”*

When health care professionals do not adequately understand and acknowledge the full lived reality of chronic illness, they contribute toward women’s loss of self-agency (Kralik, 2002, p. 146).

*I’ve spent all these years trying alternately to repudiate  
and to control my wayward body, to transcend it one way or another,  
but MS rams me right back down into it.*

(Nancy, a woman with MS, quoted in Mairs, 1989, pp. 235-236)



*I used to have a lot of patience; I could bear anything.*

*I don't think I was even aware of it. But now my body tells me. I can't control my body.*

(A woman with lupus, quoted in Charmaz, 1995, p. 664)

Another powerful loss associated with self-agency is a woman's inability to control her body, a body that she must now give over to medical caregivers, treatment protocols, and the disease itself (E. J. Cassell, 2004/1991, p. 39; Plach et al., 2004a). Ironically, in the United States, the trend is toward medicalization of suffering on a broad scale (Badaracco, 2007), such that people seek greater control over their bodies through biomedical "cures" for anything that makes them unhappy, including (and perhaps especially) aging. Women with RA, MS, and lupus may experience more control or less control over their bodies through their relationships with biomedical caregivers. A feeling that she lacks control over her body may generalize to all aspects of life that are now beyond her ability to control as a result of unpredictable disease symptoms (Giffords, 2003, p. 66).

### **Spiritual losses.**

*My disease has affected every area of my life.*

*I always think about it, even when it's in remission.*

(A person with RA, quoted in Aguilar, 1997, p. 171)

Spiritual losses associated with autoimmune disease are the most likely type of losses to remain unacknowledged because spiritual dimensions of illness are themselves

marginalized within health care communities and their respective bodies of literature. In addition, the kinds of public theology readily used to understand physical pain and suffering often use moral or sacrificial language that is life-limiting to women with chronic conditions (as I will elaborate in Chapter Three).

Many patients want to discuss spirituality and religion in relation to their health conditions, particularly when illnesses become more serious or life-threatening (MacLean et al., 2003). However, as I noted in Chapter One, members of the medical community are generally not equipped, available, or eager to discuss spiritual issues with their patients, and mental health counseling professionals typically do not explicitly address spirituality with their clients. I will provide a more thorough evaluation of these contexts of care for women with autoimmune diseases in Chapter Four.

A growing body of medical and psychological literature addresses spiritual and religious concerns of women with autoimmune diseases, but the majority of health studies only hint at spirituality under the umbrella of existential issues (e.g., Danoff-Burg & Friedberg, 2009). Unless they are specifically developed to measure religious and spiritual well-being, religious or spiritual coping, or spiritual dimensions of illness experience, instruments used to measure patients' Quality of Life<sup>6</sup> frequently neglect the spiritual dimension, implicitly suggesting that patients should also focus on physical and (to some degree) emotional aspects of the illness experience (O'Connell & Skevington, 2007, p. 78; see also Vander Zee, 2002, p. 183).

---

<sup>6</sup> Examples of instruments used to study spirituality include the Serenity Scale (Kreitzer, Gross, Waleekhachonloet, Reilly-Spong, & Byrd, 2009), the RCOPE Scale (Pargament, 1997), and FACIT-Sp Scale (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002).

Certainly diagnosis and subsequent coping with an incurable disease will have a significant impact on a woman's spirituality. It is common for people to experience a spiritual crisis when confronted with pain and serious illness (Agrimson & Taft, 2008, p. 454; Doka, 2009, p. 105; Pargament, 2007, pp. 113, 243). The unknown cause, unpredictable nature, and uncertain prognosis of RA, MS, and lupus prompt women with these conditions to consider spiritual questions about ultimate meaning and the purpose of suffering, good and evil, culpability, justice, the involvement of God/the transcendent in the human arena, and personal relationships with God/the transcendent (Becker, 1999, p. 65; Boss & Couden, 2002, p. 1353; Doka, 1989b, p. 239; Doka & Aber, 2002, p. 229; Gall & Cornblat, 2002; Gall & Grant, 2005, p. 520; Jones & Faull, 1999, p. 368; Puchalski, 2006b, p. 65; Reynolds & Prior, 2003, p. 1238; Rowe & Allen, 2004, p. 62; Russell et al., 2006, p. 66). Some spiritual questions may be quickly resolved within the context of a woman's embedded spiritual belief system; others may require more deliberative theological reflection, a topic addressed in greater detail in Chapter Three.

*Sometimes I sat and looked at people, people were strange to me, I was not like them.*

*I sometimes simply walked, aimlessly. There was nothing nice left, there was no God.*

(Jill, a woman with MS, quoted in Barrett, 1995, p. 163)

A woman with RA, MS, or lupus may experience loss of spiritual beliefs, particularly her understandings of or her faith in God/the transcendent and her understandings of how good and evil manifest in the world (Doka & Aber, 2002, p. 223).

A woman whose self-worth is challenged by disease may believe she is no longer worthy of being loved, and she may experience the loss of a loving relationship with God/the transcendent (Mann, 1982, p. 7). A woman may also experience spiritual disenfranchisement when other people impose on her their beliefs about disease without considering how she understands her illness (e.g., “It’s God’s plan.” or “You have created this illness to teach yourself a lesson.”).

A woman with an autoimmune disease may also experience the loss of spiritual practices, corporate and individual. These losses might include the ability to travel to a place of worship, fully participate in faith community activities (e.g., she may no longer be able to participate in late-night prayer vigils because of her increased need for sleep), or maintain personal spiritual disciplines (e.g., she may not be able to sustain periods of fasting when medications taken without food upset her stomach).

Women may hide their diagnoses from others for fear of being discriminated against (e.g., in order to maintain employment) or because they feel ashamed of emotions related to the illness (e.g., they may be angry at God/the transcendent or fear for their future instead of trusting in God/the transcendent) (Kauffman, 1989, p. 28). As a result of lying or withholding information, women may experience moral struggles, struggles that are themselves disenfranchised due to fear and/or shame (Grytten & Mäseide, 2005, p. 233; Kauffman, 1989, p. 26). Disenfranchised losses have a circular nature: what is not acknowledged further complicates grief in general.

In summary, there are many opportunities for women with RA, MS, and lupus to experience disenfranchised losses as a result of their illnesses. In Chapter Five, I propose

ritual practices within the context of spiritual direction to help women with autoimmune diseases acknowledge—for themselves and for others—these types of losses. As I have described here, a woman’s spiritual well-being and relationship with God/the transcendent can be disrupted by losses associated with an autoimmune disorders. Her spirituality can also serve as a significant resource as she copes with years of living with an unpredictable disease.

### **Spiritual Struggles, Health and Well-Being**

*If you’re going to survive, you have to develop your spirituality . . .*

*you have to be very strong . . . you have to stay centered.*

(Margaret, a woman with MS, quoted in Fong et al., 2006, p. 701)

A growing corpus of literature demonstrates that a relationship exists among religion/spirituality, health, and well-being.<sup>7</sup> Although critiques of empirical research in the field of religion and health point out simplistic and inconsistent operational definitions, lack of diversity in participant populations, inherent Christian bias, predominantly cross-sectional design,<sup>8</sup> and other methodological weaknesses (Badaracco, 2007; Kaye & Raghavan, 2002; Koenig & Cohen, 2002b; Pargament, 2007), it is possible to draw some useful conclusions from this body of work.

---

<sup>7</sup> Recall that in Chapter One I defined *well-being* as a subjective measure of how a person experiences inner and outer harmony in all dimensions of life, harmony that may exist in spite of disease or impairment.

<sup>8</sup> Cross-sectional quantitative studies indicate correlational relationships between variables based on observations at a given point in time. Longitudinal studies, which follow participants over a period of time, provide insights into the stability of a variable relationship, cause and effect, and prognosis.

Religious coping literature provides a useful construct for exploring relationships among spiritual struggles, health, and well-being: the spiritual orienting system. The *spiritual orienting system* (SOS) is a framework of beliefs, practices, personality, values, and experience that constitutes the person's spirituality (Pargament, 2007, p. 32). When events within and outside of the spiritual orienting system threaten, harm, or exceed the limits of the SOS, the person engages in coping to restore equilibrium. When a woman has RA, MS, or lupus, threats to her SOS might include initial diagnosis of the disease, the sense that she is unable to connect to God/the transcendent through her prayer practices, the onset of paralysis in her legs, or an incident of public discrimination.

*My faith in God [gives me hope]. My life is in His hands.*

*He's here and that gives me hope. [I say] daily prayers*

*and prayers of thankfulness and gratitude. I trust Him explicitly that I will be fine . . . .*

*I'm much more fortunate than many I know.*

(A person with MS, quoted in DiLorenzo et al., 2008, p. 1094)

In the case of illness in general and autoimmune disease in particular, the majority of people rely on religious and spiritual beliefs (e.g., faith in God) and practices (e.g., prayer, meditation, participation in a faith community) to cope (e.g., Aguilar, 1997; Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, 2003; Gall & Cornblat, 2002; Kaye & Raghavan, 2002; Keefe et al., 2001; Koenig & McCullough, in press; McCauley, Tarpley, Haaz, & Bartlett, 2008; M. Townsend et al., 2002; Wachholtz & Pargament,

2008). Religious coping can be both a help and a hindrance to health.<sup>9</sup> The majority of studies (79 percent) demonstrate at least one correlation between religion and positive health outcomes, including well-being; quality of life; increased marital stability, longevity, optimism, hope, and sense of purpose; as well as decreased depression, anxiety, pain, criminal activity, and addictive behaviors (Koenig & McCullough, in press; see also Badaracco, 2007; McCauley et al., 2008).

A woman may be able to quickly return to spiritual equilibrium and sustain her well-being and relationship with God/the transcendent, but when coping is not effective, she can experience chronic spiritual struggles. Positive religious coping (e.g., seeking spiritual support, enhancing one's relationship with God/the transcendent, benevolent reframing, collaborative coping) is generally associated with positive health outcomes (e.g., increased well-being and quality of life; decreased depression, anxiety, and pain). On the other hand, negative religious coping (e.g., deferred coping, pleading, punitive reframing) is associated with mixed results.

Negative religious coping, which is also referred to as spiritual struggle (Trevino et al., 2010, p. 379), may lead to positive spiritual growth and positive health outcomes. Some faith traditions see struggle as a necessary component of spiritual growth,<sup>10</sup> and studies have affirmed a relationship between struggle and positive experiences of growth

---

<sup>9</sup> To date, research efforts have focused on mental health (70 percent of studies) rather than physical health outcomes (30 percent of studies) (Pargament, 2007).

<sup>10</sup> For example, Christianity acknowledges the transformative power inherent within "dark night of the soul" spiritual experiences (Cross, trans. 1959), and Buddhism is grounded in the premise that life is suffering (*Buddhist scriptures*, trans. 1987).

(McConnell & Pargament, 2006, p. 1471). However, “getting stuck” in struggle is problematic (Pargament, Murray-Swank, et al., 2005, p. 258).

The relationship between chronic spiritual struggles and health outcomes was demonstrated in a two-year longitudinal study where researchers found that people who reported spiritual struggles both at the beginning and at the end of the study period showed “significant declines in quality of life and, to a marginal extent, depressed mood and functional status” (Pargament et al., 2004, p. 727). A more recent longitudinal study affirms that chronic “spiritual struggle leads to lower levels of psychological, physiological, social, and spiritual well-being” (Trevino et al., 2010, p. 386). These study results have important implications for women with autoimmune diseases who experience ongoing losses, suffering, and spiritual struggles over the course of years, circumstances that put them at greater risk of developing chronic spiritual struggles that negatively affect their health and well-being.

In this dissertation, I use *chronic spiritual struggles* to describe the experience of “getting stuck” in struggles, as described in the Pargament et al. (2004) and Trevino et al. (2010) studies. *Life-limiting* struggles or coping do not contribute to a woman’s healing or well-being, but they may not become chronic struggles if the woman is able to conserve or transform meaning or practices and restore spiritual equilibrium relatively quickly.

*My faith in God has been my effective coping skill.*

*I was diagnosed at a young age, and shortly after, an angel came to visit me.*



*I know that my guardian angel has watched over me all these years.*

(A person with RA, quoted in Aguilar, 1997, p. 173)

Looking at the relationships among spiritual struggle, health, and well-being, numerous studies affirm the positive relationship between meaning-making<sup>11</sup> and well-being for people who have chronic illnesses (e.g., Goodman, Morrissey, Graham, & Bossingham, 2005, pp. 607-608; Groarke, Curtis, Coughlan, & Gsel, 2005, p. 611; R. C. Katz et al., 2001, pp. 561-562; Kaye & Raghavan, 2002, p. 238; McPherson, 1980, p. 24; Park, 2007; Yanez et al., 2009, p. 739). Appealing to God/the transcendent is common with illness (Becker, 1999, p. 162; Vander Zee, 2002, p. 183), and the way a person understands God/the transcendent affects her well-being. For example, more positive beliefs (e.g., God/the transcendent is loving) provide a greater sense of well-being than negative beliefs (e.g., God/the transcendent is punitive) (Gall & Grant, 2005, p. 523).

In general, meaning-making in which people view their situation from a positive perspective—“benefit-finding”—results in improved well-being and adaptation to illness (R. C. Katz et al., 2001, pp. 568-569; McNulty, Livneh, & Wilson, 2004, p. 96). Even though the precise relationship between benefit-finding and the chronic illness experience is not yet understood (e.g., Mohr et al., 1999, p. 380; Pakenham & Cox, 2009, p. 373), how people assign meaning to their illnesses plays an important role in the process of living well with RA, MS, or lupus. The ways people make meaning of chronic illness is the topic of Chapter Three.

---

<sup>11</sup> In Chapter One, the definition of *spirituality* included meaning making within the context of one’s relationship to God/the transcendent.

## Summary

In this chapter, I described shared experiences of RA, MS, and lupus, including the likelihood of delayed diagnoses; the reality of pain, fatigue, and depression that act alone or in combination; and the liminal nature of these diseases. These characteristic experiences of autoimmune disease may also result in losses related to a woman's identity, her relationships with others, her sense of self-agency, and her spiritual beliefs and practices. These and other losses may be disenfranchised by the woman, members of her support community, and/or the public. This rich description of autoimmune disease—as experienced by women with RA, MS, and lupus—helps educate caregivers for the growing population of women with these conditions.

Attention to these aspects of the chronic illness experience is critical to diminish the likelihood of chronic spiritual struggles that can negatively affect a woman's health and well-being. The incurable and progressively degenerative nature of RA, MS, and lupus heightens the importance of this concern because the risk of chronic spiritual struggle does not diminish and may even increase over time for women with these conditions.

This chapter illustrates ways in which women with RA, MS, and lupus are constantly challenged to make sense of suffering and sets the stage for theological reflections on chronic illness in Chapter Three. In the next chapter, I examine various ways in which people may assign meaning to chronic illness experiences, and I consider how theology and disability studies can contribute toward more complex and contextual meaning making. I conclude the chapter by constructing provisional theological claims

about a woman's experience of living with autoimmune disease, claims that support the need for and contribute to development of a model of spiritual direction for women with these chronic health conditions.

### **Chapter Three: Theological Understandings of Chronic Illness**

*I was in [the] hospital for a week . . . On this ward, among these women,  
I came to know what MS could mean and to experience second-hand the diagnosis.*

*One woman who talked to me asked many times “Why me?”*

(Jill, a woman with MS, quoted in Barrett, 1995, p. 162)

A pastoral theological response to chronic illness begins with human experience. The descriptive work of Chapter Two articulates physical, psychological, and spiritual dimensions of autoimmune illness experiences from the perspective of women who have RA, MS, and lupus. Chapter Two also points out that the way people make meaning of their illness experiences contributes to their health and well-being. In order to develop a richer understanding of the spiritual dimension of living with a chronic health condition expressed through meaning making, the current chapter brings additional resources into conversation with the thick description of autoimmune disease.

I begin with a process (see Figure 1) of theological reflection that first surveys pastoral care, psychological, and religious coping literature to describe ways meaning making emerges out of and affects the chronic illness experience, including its relationship to spiritual struggle. Second, I use disability theologies and theological paradigms for understanding suffering to examine the underlying theological implications

of the three most common models<sup>1</sup> of understanding illness and disability: the moral model, the biomedical model, and the social model.<sup>2</sup> The third step brings these theological reflections into dialogue with Chapter Two's thick description of the experience of living with rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus in order to make provisional theological claims about a woman's psychospiritual experiences of autoimmune disease and her unique needs for care. The complex critical correlational work in this chapter can be depicted as:

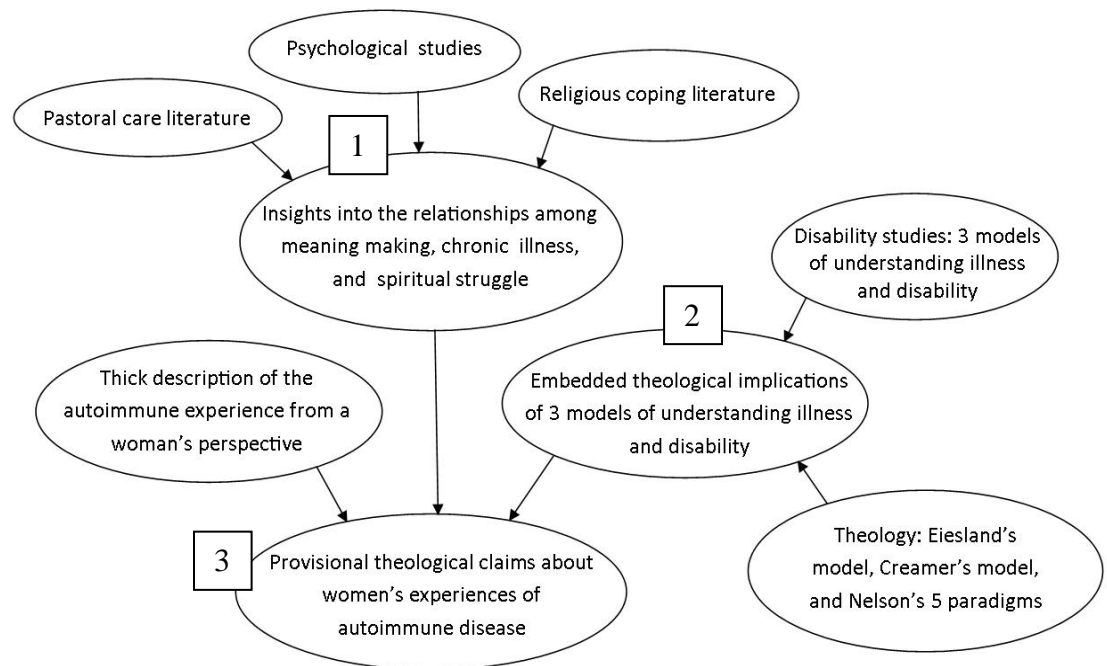


Figure 1. Chapter Three process diagram

<sup>1</sup> In this chapter, a number of terms name theoretical frameworks for understanding illness and disability. I refer to these constructs as their authors or explicators have referred to them (e.g., Nelson uses *paradigm* and *view*, Creamer uses *model*).

<sup>2</sup> I recognize that these models privilege Western views of the physical body and do not account for alternate views (e.g., energetic understandings of the body described in traditional Chinese medicine and Ayurveda). This dissertation focuses on the U.S. context and on the three most common views of illness and disability found here. Caregivers should be aware that more diverse understandings of the body exist.

The appropriate next step will be to develop a course of action, a spiritual care response to these provisional claims. That work begins in Chapter Four with the evaluation of potential approaches to spiritual care for women with RA, MS, and lupus and culminates in Chapter Five with a model of spiritual direction for this population.

### **Meaning Making and Chronic Illness**

*I've got such richness, shall I say, such meaning.*

*I've found the meaning of life, that's the way I look at it.*

*My meaning is that I've found the joy in this life, and therefore for me to go through anything, it doesn't matter really, in one way, because I reckon that they are testing times . . . You see. He never says that you won't have these things . . . He comes with us through these things and helps us to bear them.*

(Betty, a woman with RA, quoted in G. Williams, 1984, p. 194)

Meaning making is a fundamental aspect of the chronic illness experience, such that “no understanding of human illness or suffering will be possible without taking it into account” (E. J. Cassell, 2004/1991, p. 36). Illness has been called a “crisis of meaning” (Pattison, 1989, p. 34), and illness demands a meaning making response to facilitate healing (e.g., Davis, 2001, pp. 142-143; Ironside et al., 2003, p. 173; Kinsley, 1996, p. 186; Kleinman, 1988, p. 22; Pattison, 1989, p. 34; Russell et al., 2006, p. 66).<sup>3</sup> In

---

<sup>3</sup> Thernstrom's (2010) anecdotal evidence supports these claims. While conducting research on chronic pain, Thernstrom explored ways to cope with her own painful medical condition (e.g., recording her thoughts in a pain diary). She observed: “Although my rheumatologist had suggested keeping the diary as a helpful tool, the diary itself became a place for embroidering my pain with pernicious meanings. When, as

addition, psychological literature on grief theory asserts that “*meaning reconstruction in response to a loss is the central process in grieving* (Neimeyer, 1998)” (Neimeyer, 2001a, p. 4, emphasis in original). These contentions are important when considering meaning making in the context of autoimmune disease. Many losses associated with autoimmune conditions may be experienced twofold: as a specific loss of identity, relationship, self-agency, etc. and as an affront to the woman’s spiritual orienting system (Sapey, 2004, p. 98; see also Gall & Grant, 2005, p. 519). With chronic illnesses, meaning making is necessary in response to both the illness itself and to the losses that accrue as a result of the illness.

Within the medical literature, the meaning of an illness is considered one aspect of a person’s *illness perceptions*, which “include beliefs about what caused the illness, how long it will last, its expected effects, and controllability (Skelton & Croyle, 1991)” (Sterba et al., 2008, p. 221, see also Graves, Scott, Lempp, & Weinman, 2009, p. 422 and Groarke, Curtis, Coughlan, & Gsel, 2005, p. 610). Although illness perceptions affect health (e.g., negative illness perceptions are correlated with higher rates of depression and anxiety), they represent a broad view of illness experience that is beyond the focus of this dissertation. I am interested in spiritual struggles associated with autoimmune conditions, and spiritual struggles correspond most closely with one aspect of illness perceptions: beliefs and meaning making about illness causation.

---

a journalist, I had the opportunity to read other patients’ pain diaries, I was struck by how many others did the same” (p. 10).

*Making meaning*, as it pertains to illness, has been defined in psychological literature in a number of ways, including “benefit-finding . . . sense-making . . . meaning-as-comprehensibility . . . [and] meaning as significance” (Davis, Nolen-Hoeksema, & Larson, 1998, pp. 561-570; see also Pakenham, 2008, p. 94). Defining *meaning making* in these ways

strongly suggests that we are self-consciously active, take deliberate initiative, and bring new meanings into existence as we grieve. . . . But there is also a strong sense in which much of what we do is a matter of “meaning finding.” *Finding* in this expression strongly suggests that at other times we are less self-conscious in what we do, are more passive or receptive, and return to or encounter something already established, and often not of our own doing, as we mourn. (Attig, 2001, p. 34, emphasis in original)

I follow Attig’s approach to *meaning making* as a term that includes both passive and active discovery, conservation, and construction of understandings. Working specifically within the context of the chronic illness experience, and engaging the definition of spirituality in Chapter One that includes meaning making, I focus on *meaning making* related to the causal explanation of an illness within the context of a person’s relationship with God/the transcendent (see Bury, 1982, p. 179; Davis, 2001, p. 143).

*My faith in God [gives me hope]. My life is in His hands.*

*He’s here and that gives me hope. [I say] daily prayers*

*and prayers of thankfulness and gratitude. I trust Him explicitly that I will be fine . . .*

*I’m much more fortunate than many I know.*

(A person with MS, quoted in DiLorenzo et al., 2008, pp. 1093-1094)



People who identify themselves as more religious and/or spiritual are more engaged in making meaning of their illness experiences than people who do not think of themselves as religious/spiritual (Davis et al., 1998; Pakenham, 2008, p. 93). This may occur because one purpose of religion and spirituality is “to interpret life” (Abraham, 1989, p. 250). Another factor may be that when people find themselves in situations that are beyond their understanding or control, they turn to that which may provide answers or a sense of control, such as God/the transcendent (Gall & Cornblat, 2002; Pargament & Hahn, 1986).

When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares that meaning. Such an experience need not involve religion in any formal sense; however, in its transpersonal dimension it is deeply spiritual. (E. J. Cassell, 2004/1991, p. 43)

*Having this disease has made me change the way I look at illness and disease.*

*I actually am unable now to be optimistic.*

*My attitude has changed, I used to be the other way round.*

(A woman with RA, quoted in Lempp et al., 2006, p. 113)

Generally speaking, “illness may significantly increase an individual’s vulnerability to spiritual struggles” (McConnell & Pargament, 2006, p. 1472). Not every person experiences spiritual struggles with illness (Fitchett et al., 2004; Fitchett & Risk, 2009),<sup>4</sup> but the likelihood increases with autoimmune conditions because a woman’s

---

<sup>4</sup> In one study, 48 percent of patients said they experienced *religious* struggles related to their illness, and 15 percent of participants described their struggles as “moderate to high” (Fitchett et al., 2004, p. 179). I

spiritual orienting system is continually threatened by losses, chronic pain and fatigue, emotional instability, increased incidence of depression and anxiety, and diminished functional independence (Gordon et al., 2002; Sidell, 1997; Vandecreek et al., 2004; J. Williams & Koocher, 1998). As new crises occur with the degenerative nature and the flare/remission cycles of RA, MS, and lupus, women are prompted to respond with perpetual meaning making (Russell et al., 2006, p. 66). If a woman's spirituality lacks the "breadth" or "depth" needed to make sense of her suffering on an ongoing basis, she is at risk of developing chronic spiritual struggles (Pargament, 2007, p. 293).

Studies with women who have autoimmune diseases demonstrate an association between meaning making and spiritual struggle. Women with MS who did not engage in meaning making were "at risk of *becoming caught in a cognitive rumination trap* where they struggle to integrate situational appraisals of their illness with their global meaning structures" (Pakenham, 2008, pp. 102, *emphasis added*). Women with RA who engaged in meaning making, but became stuck in chronic spiritual struggle (e.g., continued to ask questions such as "Why me?"), had "greater functional problems and a greater sense of helplessness" than women who were able to reestablish spiritual equilibrium through meaning making (Affleck, Pfeiffer, Tennen, & Fifield, 1987, p. 927).

---

would expect the actual percentage of people experiencing *spiritual* struggles in relation to illness to be much higher for two reasons. First, this study used the Negative Religious Coping section of the Brief RCOPE Scale to assess struggle. This section consists of only seven statements that address a limited range of struggles, and the statements use "God" language in ways that do not resonate with broader understandings of spiritual struggles. Second, people sometimes experience "illusory spiritual health" where "they appear 'healthy' on self-report measures of religiousness, but in fact, when assessed clinically are found to be religiously or spiritually 'distressed'" (Hall et al., 2008, p. 153).

Pain researchers have also demonstrated a relationship between meaning making and well-being:

certain beliefs and attitudes [are] virtually ‘toxic’ in their power to perpetuate and aggravate pain experiences. The chief example is called “catastrophizing”. . . *That aspect of catastrophizing called “ruminating” appears to be particularly significant in making bad pain even worse.* (Underwood, 2006, p. 6, emphasis added)

These studies indicate the importance of meaning making to help women with RA, MS, and lupus prevent or alleviate getting stuck in chronic spiritual struggles that threaten health and well-being.

The strength and content of spiritual beliefs and practices, including meaning making, have a profound effect on a person’s ability to cope with chronic illness and sustain well-being (Levin, 2001). It is vital for caregivers to understand how women with RA, MS, and lupus are making meaning of their conditions. It is also important for caregivers to be aware of how they personally make sense of illness and disability so they do not inadvertently impose their beliefs on careseekers. Such self-reflection is a critical first step in using an intercultural approach to spiritual care (described in Chapters Four and Five).

### **Toward Theological Claims about Chronic Illness**

With few exceptions (e.g., Muldoon & King, 1991; Pattison, 1989), little constructive theological work has been published about chronic illness. The fields of disability studies and disability theology, however, offer useful constructs that I will

examine for their applicability to the experience of chronic illness.<sup>5</sup> Experiences of chronic illness and disability are often intertwined in theory and in reality; experientially, both disease and disability are rooted in embodied impairment. In addition, there is a growing trend in rehabilitation literature (e.g., Livneh, 2001) to describe experiences of chronic illness and disability in the aggregate (e.g., as “CID”), and other psychological literature uses disability studies work to explicate models of understanding chronic illness (e.g., Walker, Jackson, & Littlejohn, 2004). I follow in these footsteps by using disability studies and disability theologies to illuminate the meaning making process of chronic illness.

Because disability work relates to a unique set of experiences, I also introduce Nelson’s (2003) five paradigms of understanding suffering (moral, redemptive, eschatological, radical, and ambiguous suffering) as lenses into the embedded theological implications of the moral, biomedical, and social models of understanding chronic illness and disability. It might seem that only moral model understandings would have theological implications. However, all explanations of illness may be

moral explanations in the very broadest sense of the term [because] it is also possible to construe them as spiritual explanations as they deal with what is of utmost importance to people, invite belief and commitment at a most fundamental level of life, and project forward to future hope. (Pattison, 1989, p. 41)

---

<sup>5</sup> Although the term *disability* can be problematic because its definition is highly contextual (e.g., disability may describe a physical or mental limitation or an instance of social oppression), models of understanding disability are nonetheless useful to understand chronic illness.

## **Disability theologies.**

There are but a few scholars who address the religious and spiritual dimensions of disability. Some of the better known theologies of disability focus on social issues of access and inclusion, particularly within faith communities (e.g., Black, 1996; Block, 2002). For insight into ways of making meaning of the chronic illness experience, I turn to Eiesland (1994) and Creamer (2009).

One of Eiesland's goals is normalizing disability, and she moves toward this goal by accentuating the image of Christ depicted in Luke 24:36-39:<sup>6</sup>

Here is the resurrected Christ making good on the incarnational proclamation that God would be with us, embodied as we are, incorporating the fullness of human contingency and ordinary life into God. In presenting his impaired hands and feet to his startled friends, the resurrected Jesus is revealed as the disabled God. Jesus, the resurrected Savior, calls for his frightened companions to recognize in the marks of impairment their own connection with God, their own salvation. In so doing, this disabled God is also the revealer of a new humanity. . . . underscoring the reality that full personhood is fully compatible with the experience of disability. (p. 100)

Eiesland further pushes the boundaries of the image of a “disabled God” with her radical conceptualization of “God in a sip-puff wheelchair” (p. 89). The disabled God is a

survivor . . . a simple, unself-pitying, honest body, for whom the limits of power are palpable but not tragic. The disabled God embodies the ability to see clearly the complexity and the “mixed blessing” of life and bodies, without living in despair. (Eiesland, 1994, p. 102)

With these images of God, Eiesland claims disability—and by extension, other chronic limiting conditions—as a normal part of the human experience. A disabled God

---

<sup>6</sup> In Luke 24:36-39, we find Jesus' disciples puzzling over their encounter with the risen Christ at Emmaus: “While they were talking about this, Jesus himself stood among them and said to them, ‘Peace be with you.’ They were startled and terrified, and thought that they were seeing a ghost. He said to them, ‘Why are you frightened, and why do doubts arise in your hearts? Look at my hands and my feet; see that it is I myself. Touch me and see; for a ghost does not have flesh and bones as you see that I have.’” (New Revised Standard Version)

presents an image that is both perfect in its divine nature and imperfect in its wounded embodiment. Eiesland presents “an ambiguous Christology of fluid embodiment” that breaks the mold of binary categories (Hays, 2010). This image may resonate with the experiences of women who challenge binary constructions of *healthy* and *unhealthy*. When Eiesland notes that “Christ’s disfigured side bears witness to the existence of ‘hidden’ disabilities” (Eiesland, 1994, p. 101), she helps women connect God’s hidden disabilities with the often invisible nature of disabling autoimmune experiences, such as pain, fatigue, depression, cognitive losses, and degenerative joint and tissue damage. Eiesland’s disabled God offers one way that women with RA, MS, and lupus can begin to answer the question “Why me?” If disability is one dimension of God, it should be no surprise that it happens to people as well. As one woman with rheumatoid arthritis said: “*I’ve come to think ‘Well, why not you? We’re not special. It just happens that way’*” (Reynolds & Prior, 2003, p. 1238).

It is important to note, however, that the radical image of a disabled God might prove untenable for some women who would not be able to reconcile within their embedded belief systems an image of God that does not ultimately transcend wounds (e.g., some women might desire a more traditionally powerful understanding of God/the transcendent). This image might also prove problematic for women who do not ascribe to understandings of the transcendent that take or can be depicted in theistic or human form (e.g., women within the Muslim tradition or women who relate to the transcendent through nature).

Eiesland's work might prove useful for women in other ways. She notes: "The difficulty for people with disabilities has two parts really—living our ordinary, but difficult lives, and changing structures, beliefs, and attitudes that prevent us from living ordinarily" (p. 13). The first half of this observation resonates with the experience of ongoing losses that make up everyday life for women with autoimmune diseases. The latter half of Eiesland's assertion supports women as they strive to overcome power dynamics and social discourses that facilitate disenfranchisement of loss experiences. Although not every woman will seek a redemptive outcome from her illness (e.g., advocating for women's experiences to be valued equally alongside physicians' opinions), those who want to pursue such a path can find support from Eiesland's theology for their efforts.

Creamer (2009) offers what she calls a "gifts model" (p. 95) of disability. This "theology of limits" does not embrace notions that all disability/illness can be redemptive or that the best form of coping with limitations is benefit-finding. Rather, Creamer seeks to alleviate the negative moral baggage frequently associated with limits as she encourages a shift in thinking toward a view of limits as "*good*, or, at the very least, not evil" (pp. 94-95, emphasis in original). She qualifies this statement in this way:

the limits model does not stipulate that *all* limits are necessarily "normal" or even "good." . . . It is not the argument of the limits model that we should all want to be disabled, or even that we should embrace and be happy about all our limits. The importance of this model is its demand that limits, as well as the diversity of ability, must be seen as integral elements of our understandings of self and other, as key characteristics for reflection in a theological anthropology. . . . The limits model demands that we reject unrealistic ideals or illusions of perfection, recognizing that such images lead to unproductive and dangerous dualisms. (pp. 109-111)

In addition to her assertion of the amoral nature of limits, Creamer makes two other “significant religious claims”: “limits are an *unsurprising* characteristic of humanity. . . . [and] limits are an intrinsic aspect of human existence” (p. 94). These claims work in the context of chronic illnesses as well. As noted in Chapter One, statistics speak to the growing probability that each of us will one day experience a chronic illness. Within the context of degenerative autoimmune diseases, limits are a certainty.

Creamer works to demystify the category of disability by revealing its “porous,” contextual nature: “disability is no one thing” (p. 96). Similarly, every chronic illness experience is unique. The uniqueness of experience creates practical problems when theological reflection meets the reality of day-to-day living, and Creamer notes the need for “criteria for evaluation, to help us understand which limits are ‘good’ and which are ‘wrong,’ which to embrace and which to creatively overcome” (116). This is an important point for women with RA, MS, and lupus to consider in their meaning making as they must routinely weigh their needs for self-care against the demands placed on them by self, family, and society.

As Creamer notes, the theology of limits is a work in progress (p. 117). As the limits perspective is further developed, it is important that it does not inadvertently further disenfranchise experiences of loss associated with autoimmune diseases by suggesting that because everyone has limits, women with chronic illnesses should not expect acknowledgment of losses associated with their particular experiences of



limitation. This concern echoes critiques of social model understandings of disability that diminish individual suffering:

claiming that everyone is “disabled” in some way because everyone has some limitations and “imperfections” . . . can lead to underestimating the struggles of people whose limitations of sufferings are much greater because of their physical and/or mental health conditions and because of the many socially constructed obstacles in their lives besides their “Otherness.” (Wendell, 1996, p. 66)

Eiesland and Creamer both acknowledge the importance of recognizing and addressing the socially constructed nature of some limitations/disabilities. For the woman with an autoimmune disease who experiences very real pain and fatigue located within her body, it is important to recognize that her limitations are imposed as much—or perhaps more—from within as from outside sources.

### **Paradigms for understanding suffering.**

Nelson’s (2003) five paradigms for understanding suffering<sup>7</sup> offer additional theological resources for meaning making in relation to chronic illness experiences. Although Nelson comes from the Christian tradition, the breadth of understandings included in these paradigmatic views makes them accessible to people of diverse backgrounds. Nelson’s paradigms can be summarized thusly:

In the *moral* paradigm, people experience suffering as a result of sin or wrongdoing (their own, others, and corporate sin/wrongdoing) (p. 400), or they understand suffering as lesson from God/the transcendent (p. 400). The world remains a

---

<sup>7</sup> Nelson (2003) uses the words *suffering* and *evil* in her work, defining *evil* as “both the experience of suffering and the fear that suffering subverts all meaning and order in the world” (p. 398). Given this definition, her reflections can be used to reflect on what might be described as “innocent” or natural suffering that arises from chronic health conditions.

place of hope (p. 400) even as an omnipotent and transcendent “God is complicit in evil” through the act of creation (p. 401), punishes sinners, and teaches people through suffering (p. 400). Although people holding a moral view of suffering may find it difficult to reflect on possible lessons in the midst of crisis, this paradigm supports engagement with God/the transcendent in the meaning making process. The moral view also helps people accept situations they cannot change by putting their trust in something greater than themselves. The moral view may also help some women take appropriate accountability for monitoring their illness and seeking health care.

*Radical suffering* is a view in which God/the transcendent is often not apparent (p. 404). In fact, the person who is suffering may experience a sense of abandonment or distance from God/the transcendent. However, God/the transcendent may also be experienced as relational and willing to change as a result of human protest (p. 403). Christians may experience Jesus as a co-sufferer (p. 403). The person who suffers is the focus in this paradigm as she laments her situation (p. 403). Although giving voice to pain and loss is beneficial—particularly in thinking about disenfranchised losses—this understanding of suffering does not address meaning making.

In the *ambiguous creation* paradigm, God/the transcendent is associated with mystery and complexity. The world is finite and diverse, a place where “suffering and conflict are implicit” (p. 406). The person who suffers may be complicit in suffering through free will (p. 405), even if harm is unintentional (p. 406). People are called to respond to suffering with compassion (p. 407). This view provides an understanding of the human experience that may help sufferers bond in communal acknowledgment of the

existence of an ambiguous world in which good and evil, health and illness, exist together. However, women may find this paradigm lacking as they make meaning of chronic illness; if disease just “happens,” then how are we to cope with it?

The *eschatological imagination* paradigm claims that God is “the advocate of the oppressed, judge of human cruelty, and fellow sufferer” (p. 409), the latter embodied in the person of Jesus. People who suffer will be vindicated, if not now, then ultimately (pp. 408-409). People find hope and meaning as they resist suffering through “simple acts of justice and kindness” (p. 407) and through “sacrificial act[s]” (p. 408). People with chronic illnesses may appreciate the way this view offers hope in the good moments of everyday life as well as in the promise of ultimate relief.

In the *redemptive suffering* paradigm (p. 409), people are called to reconcile themselves with God in order to experience transformation (p. 411). They may also resist suffering through acts of kindness or sacrifice, such as advocacy for others who suffer similarly (p. 410) or by “turning the other cheek” (p. 412). This paradigm can offer hope and support meaning making by providing opportunities to frame suffering in terms of a higher purpose, and it can motivate people “to work for the end of such suffering” (p. 412).

### **Models of Understanding Chronic Illness**

*They say that these diseases are illnesses you manufacture yourself.*

*There are antibodies that become active and go places*

*where they are not supposed to go. They choose something they've not gobbled up yet,  
but they can also come back to places they have already been . . .*

*I don't know if it has anything to do with it, but if you don't like yourself, it can come.*

*For a long time I was in a state where I couldn't enjoy myself.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 594)

People with chronic illnesses initially make meaning of illness experiences by relying on embedded beliefs that they have adopted or constructed over time. Studies find that embedded beliefs about illness are tenacious (Hunt, Jordan, & Irwin, 1989, p. 949; see also Kralik et al., 2001, p. 596), even in the face of contradictory evidence (Goodman et al., 2005, p. 610), which is typically woven into existing narratives (Hunt et al., 1989, pp. 952, 955, see also Bury, 1991, p. 455). Caregivers need to be aware of a woman's embedded understandings of her autoimmune experience in order to monitor the way these understandings influence treatment compliance, coping, the potential for chronic spiritual struggles, and health outcomes.

### **Metaphors for chronic illness.**

*Before I came home from the doctor's office, I stopped off in White Plains,  
and I went to Bloomingdale's and I bought ten pairs of shoes. That's what I did.*

*Here I have MS and I went out and I bought ten pairs of shoes, boots, shoes.*

*Dr S. said, "Wear low-heeled shoes. Don't wear the high heels."*

*So I bought espadrilles.*

(A woman with MS, quoted in Duval, 1984, p. 636)

People often express embedded understandings of their illness experiences through images and metaphors. Medical literature has captured a variety of metaphors for illness. For example, the following images are related to multiple sclerosis: wheelchairs refer to the disabling nature of the disease, cyanide depicts a condition so disabling that it prompts a person to consider suicide, vegetables refer to a person's progression toward a vegetative or near-vegetative state, rotting flesh connotes the slow degenerative progression of the disease, and time bombs refer to the unpredictable nature of the disease (Duval, 1984, p. 637). Chronic illness has also been likened to an earthquake because of the wide-scale damage and trauma it causes (Spencer-Benson, 2003, p. 93), lupus has been called "a bug, something foreign that won't go away" (Taïeb et al., 2010, p. 595) and "the wolf" (Miles, 2009, p. 5), which plays on the scientific name for the gray wolf: *canis lupus*. One woman suggested that lupus was "eating" her (Taïeb et al., 2010, p. 594), and two women compared autoimmune disease to gradual suicide:

*It's a disease you create for yourself, when deep down you want to die.*

*Lupus doesn't happen by accident,*

*it's part of a self-destroying process that has been ingrained in me.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 594)

and

*It's a self-suicide of the body, because I didn't have the courage to do it myself.*

*The body manufactures its own antibodies that destroy it.*

*I've realized it's self-destruction that comes from yourself.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 594)

Life with chronic illness has also been described as a “response shift” (Sprangers & Schwartz, 1999), “a positive challenge” (Stamm et al., 2008, p. 665), “shifting sands, staying afloat, weathering the storms, rescuing oneself and navigating life” (Whittemore & Dixon, 2008, p. 177), and moving between “ordinariness and extraordinariness” (Kralik, 2002, pp. 146-150). I have previously mentioned understandings of chronic illness as “shifting perspectives” (Paterson, 2001) and “biographical disruption” (Bury, 1982).

Metaphors provide fluid ways of describing experiences that are difficult to articulate (Becker, 1999, p. 65), and they facilitate the meaning making process (Arvay, 2001, p. 224). The tendency to disenfranchise losses associated with chronic illness—to essentially silence the losses—points to one reason why women may have difficulty expressing the meaning of their experiences with RA, MS, and lupus.

The metaphor of challenge/war/battle—which includes images of autoimmune diseases as “the enemy,” (Charmaz, 1991, p. 663; Muldoon & King, 1991, p. 102; Reynolds & Prior, 2003, p. 1234) “bullies,” “terrorists” (Miles, 2009, p. 5), and “an atomic bomb” (Taïeb et al., 2010, p. 594)—is frequently found in the literature (Taïeb et

al., 2010, p. 597; see also Reynolds & Prior, 2003, p. 1225). Use of such a culturally-embedded metaphorical reference may help women who seek public acknowledgment and legitimization of their experiences (Glucklich, 2001, p. 47). Women with autoimmune conditions may also find metaphors to be a helpful mode of communication because of the chronic pain associated with these diseases. As the McGill Pain Questionnaire<sup>8</sup> (Melzack, 1975) affirms, people find it difficult to describe the raw experience of pain, let alone its meaning. Metaphors may also be helpful in the liminal reality of chronic illness, describing the in-between state between what was and what may be (Becker, 1999, p. 60).

Underlying metaphors for chronic illness are embedded beliefs about the cause of disease. For example, the metaphor of *self-suicide* implies that the woman is at least partially responsible for the disease, while the metaphor of *weathering the storm* suggests she may be reacting to something that is overpowering her from the outside. In Western societies, we find three primary models for attributing cause to illness and disability: the moral model, the biomedical model, and the social model.

For explanatory purposes, I describe the three models independently. However, people are complex, and caregivers can expect careseeker understandings to incorporate aspects of one or more models in their meaning making. For example, I believe that I have rheumatoid arthritis because human bodies are finite and vulnerable to inner and outer catalysts that upset the balance within this fragile physiological system (a biomedical understanding of disease). At the same time, I believe that RA serves a

---

<sup>8</sup> The McGill Pain Questionnaire helps people articulate their pain experiences using a variety of descriptors (e.g., pulsing, stinging, agonizing) and scales (1-mild to 5-excruciating).

pedagogical purpose in my life, shaping me as a spiritual being (a moral understanding of illness).

**Moral model of understanding illness.**

*It's the old Adam, we've all got to be ill.*

(Gill, a woman with RA, quoted in G. Williams, 1984, p. 191)

Religion and health have been intertwined for thousands of years. Before people had the ability to look inside the human body to understand the cause of illness, they looked outward to the supernatural agents they believed were in control of their fate. The moral model attributes illness, pain, and disability to the whims of spirits, demons, and gods for punishment, sport, teaching, or favor (Koenig & McCullough, in press, pp. 26-27; Pattison, 1989, pp. 38, 88). Even with daily announcements of new scientific discoveries and medical advances, the moral model remains the most relied upon paradigm for understanding illness throughout the world.

The moral model does not separate body and spirit. Biological soundness or “purity” represents the ideal for humanity as a healthy body reflects a healthy soul (Betcher, 2001, p. 342). This view has been so predominant throughout history that

at the Fourth Lateran Council (1215) the church declared that because sickness was often caused by sin, a physician’s first duty when called to take care of the sick was to summon a priest. . . . In the sixteenth century, the church required physicians to swear that they would stop treating a patient if, after three days, the patient had not made confession backed by a statement to prove it. In the eighteenth century, Catholic physicians who treated patients who had not confessed were forbidden to continue to practice medicine. (Kinsley, 1996, p. 105)



Adages such as “it’s part of God’s plan” (Doka & Martin, 2002, p. 343; Russell et al., 2006, p. 72), “everything happens for a reason” (Pakenham, 2008, p. 99) and “it’s fate” (Taïeb et al., 2010, p. 594), as well as beliefs that illness fulfills a New Age “Law of Attraction” or satisfies divine or karmic justice for sin or wrongdoing are commonly associated with moral model understandings (e.g., Glucklich, 2001, p. 16; Pargament & Hahn, 1986, p. 193; Taïeb et al., 2010, p. 594).

*It was almost like this [illness] has been a gift to me  
because throughout the last however many months it’s been . . . it’s almost like I have  
a new self-awareness, a new self-discovery of it.*

*Reassessed myself as a person. Appreciate myself more.*

(A person with RA, quoted in Dubouloz, Laporte, Hall, Ashe, & Smith, 2004, p. 404)

*[I was] put into a wheelchair for a reason, [I was] being knocked down to size.*

(A woman with MS, quoted in Irvine, 2009, p. 604)

Pedagogical understandings of illness (i.e., illness understood as a life lesson) also fall within the moral paradigm. People may understand illness, particularly pain associated with the illness, as “an alchemical force, like the forger’s fire, which magically transforms its victim from one state of existence to a higher, purer state” (Glucklich, 2001, p. 25). Some people embrace the notion that their illness serves a greater purpose or that they have a special relationship with God/the transcendent (Pakenham, 2008, p.

99). In this way, illness may be thought of as a divine gift that tests or builds the person's character and can be used to inspire others (Gall & Cornblat, 2002, p. 531; Pakenham, 2008, p. 99). On the other hand, people may feel that they are being punished by illness (Pakenham, 2008, p. 99; Pattison, 1989, p. 38). For many people, "it is more tolerable for a terrible thing to happen because of something one has done—and even suffer the guilt—than that it be simply a stroke of fate, a random, chance event" (E. J. Cassell, 2004/1991, p. 43).

***Moral model: Theological implications.***

*Look, I don't question the Lord, I don't ask . . .*

*He knows why and that's good enough for me . . .*

*He is looking after his own . . . and he does look after me.*

(Betty, a woman with RA, quoted in G. Williams, 1984, p. 193)

*It's a message from God, but I don't deserve it.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 595)

Nelson's moral paradigm of suffering is clearly evident in the moral model of understanding illness in cases where God/the transcendent is blamed for the onset of disease. People often feel the need to assign blame for suffering. In the case of chronic illness, "when no person can be held responsible, [people] look to the supernatural for an agent" (Gray & Wegner, 2010, p. 8). Divine reasons for bringing suffering may seem

clear or remain mysterious; regardless, someone or something is held accountable for the tragedy.

*My body isn't healthy, it isn't pure.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 595)

*[My illness is the result of] witchcraft from my previous mother-in-law . . .*

*My husband gave back the jewellery [sic]*

*from my dowry eight years after the separation . . . That confirms it for me.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 595)

Nelson's moral paradigm is also invoked when the individual believes she is accountable for her illness due to an unrelated sin or as the result of sinful behaviors, lifestyle, or personality traits that may have provoked the onset of the disease (e.g., promiscuous sexual behavior or excessive worrying). People may assume moral guilt during the course of an illness because they have not regained their health (e.g., through lack of faith) (Eiesland, 1994, p. 117; Smart & Smart, 2006, p. 31). Sometimes people try to remedy illness or alleviate guilty feelings by living as perfectly as they can in what is known as the "try harder syndrome" (Smart & Smart, 2006, p. 31). When this strategy does not work, personal guilt and/or divine blame may increase.

*[MS is] a part of life. You accept it. The good Lord sometimes sends us challenges, and this is my challenge. You make the most of it and work with it on a daily basis.*

(A person with MS, quoted in DiLorenzo et al., 2008, p. 1093)

The moral model of understanding illness also resonates with Nelson's redemptive paradigm of suffering because people often believe illness is an opportunity for personal growth or transformation. (e.g., Reynolds & Prior, 2003, p. 1238; Spencer-Benson, 2003, pp. 101-102). The eschatological imagination paradigm is evident when the person who is sick has hope for eventual freedom from disease now (e.g., through repentance or a divine miracle) or in the afterlife.

Both Eiesland and Creamer reject notions that people are personally responsible for illness or disability through sin. These theologies acknowledge the reality of the entrenched moral model of illness and disability and seek to overcome what are often life-diminishing moral views of physical limitations.

### **Biomedical model of understanding illness.**

*It's like a lot of things you have inside you, there comes a time when it develops, it's not because my life changed, but because the thing ripened, like something foreign, something I have extra to other people.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 596)

Traditionally, the advent of the biomedical model is associated with Descartes' seventeenth-century notions of mind-body dualism (Porter, 1997, p. 46). This modern, scientific view conceptualizes the human body as a machine; disease or disability represents a "defect, dysfunction, abnormality, failing, or medical 'problem'" (Smart & Smart, 2006, p. 30). Biomedicine is the dominant model and a popular secular understanding of healing in the United States. The biomedical mantra might be: "Things happen; deal with it." Causes of illness and disability include poor health habits, genetics, aging, germs and viruses, accidents, environmental toxins, and random acts of nature (e.g., Pakenham, 2008, p. 99; Taïeb et al., 2010, p. 594). Generally speaking, the biomedical model is characterized by its focus on pathophysiology, devaluation of spirituality, focus on individual responsibility for health, and the authority of medical knowledge over patients' experiences (Porter, 1997, p. 42; Walker et al., 2004).

*If women are more affected by lupus, it must be because it's genetic.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 595)

In recent decades, biomedical practitioners have recognized that many people in the United States do not adhere to strictly Western medical protocols. Many people augment medical treatments with Complementary and Alternative Medicine (CAM), such as healing touch, acupuncture, Qi Gong, massage, and prayer (Barnes, Bloom, & Nahin, 2008). These therapies are defined as CAM by that fact that they fall outside of mainstream biomedical practice, often originating in ancient practices from non-Western

cultures (M. H. Cohen, 2006). Many CAM modalities are spiritual practices as well, but biomedical consideration is more limited to what these practices help patients achieve in terms of physical and mental health without regard to the ways they might affect spiritual well-being.

Biomedical care is focused on repairing the body as machine. As such, biomedicine is best suited for acute care for conditions that can be readily cured (Muldoon & King, 1991, p. 102; Porter, 1997, p. 45). Biomedicine's relative effectiveness in providing healing for women who have with RA, MS, and lupus will be discussed in Chapter Four.

***Biomedical model: Theological implications.***

*Mind you, I sometimes wonder whether arthritis is self-inflicted . . . not consciously.*

*You know, your own body says, "right, shut-up, sit down, and do nothing".*

*I feel very strongly about myself that this happened to me. . . .*

*One part of my head said, "if you won't put the brakes on, I will" . . .*

*I'm sure that I just cut out, I just blew a fuse.*

(Gill, a woman with RA, quoted in G. Williams, 1984, p. 191)

As illustrated in the preceding quote from Gill, a woman with RA, moral judgments are implicit within biomedical model understandings of illness (i.e., Gill was stricken with RA because she overworked her body). Moral views are evident when disease is thought to be triggered by a person's behavior or temperament. Western society

judges people who do not make culturally-accepted lifestyle choices (e.g., people who smoke, people who are morbidly obese, people who do not cope effectively with stress) and assumes they have “earned” their medical conditions to some degree (e.g., Beck, 2007, p. 83; Pakenham, 2008, p. 99). People who do not follow medical protocol (e.g., people who do not follow appropriate diets for diabetes or people who practice unsanctioned complementary or alternative therapies) are held accountable for lack of cure or progress. They have sinned, so to speak, against the powerful, pseudo-religious biomedical system.

Even research on the health benefits of looking at the positive side of illness (e.g., R. C. Katz et al., 2001) may be driven by a subtle moral approach (i.e., if a patient has a positive attitude, she will cope more effectively with her illness; if her illness worsens, she may need to adjust her attitude). A moral view of illness is also invoked when people share the biomedical understanding of body-as-machine and associate their self-worth with their ability to contribute productively to society in a society that values “doing” more than “being” (Barrett, 1995, p. 161; Becker, 1999, p. 53; Crislip, 2005, p. 69; Gall & Grant, 2005, pp. 519-520).

Nelson’s eschatological imagination paradigm of suffering is implicit when people cope with illnesses in the present while holding out hope for a cure or a helpful medical development (miracle) in the future. People in Western societies place tremendous faith in the biomedical model, and this trust is reinforced by the medical community where “the underlying philosophy of medicine appears to be that there is

nothing that human beings suffer from that is not, in principle, subject to elimination by medicine” (Hanson, 1999, p. 179; see also Swinton, 2007, p. 38).

*MS is a common neurological condition and I happen to have it.*

(A person with MS, quoted in Pakenham, 2008, p. 99)

Perhaps a more sophisticated relationship between the biomedical model and views of suffering comes from the ambiguous creation paradigm which asserts that there is “natural evil” in the world, including disease and disability (Swinton, 2007, p. 51; see also Black, 1996, p. 37; Kinsley, 1996, p. 170). Eiesland and Creamer affirm the ambiguity present in the natural world, citing: “the mixed blessing of the body” (Eiesland, 1994, p. 22) and the fact that “good health is never a permanent state” (Creamer, 2009, p. 32). Although there is recognition of ambiguity within the biomedical model, this ambiguity does not extend to fluid understandings of healthy/unhealthy bodies with autoimmune diseases, and Creamer concludes that “lived experiences of disability [and chronic illness] . . . have no home within either the medical or minority [social] models” (p. 31).<sup>9</sup>

Nelson’s pedagogical and redemptive suffering paradigms may be evident when people interpret the experience of illness as a helpful, nonjudgmental message to change some aspect(s) of their lifestyle or health care. In the case of autoimmune diseases, such messages are often described as “warning signs” to slow down or find more effective

---

<sup>9</sup> The social model, described in the following section, is also known as the functional, environmental, sociopolitical, or minority model.



ways to handle stress (Pakenham, 2008, p. 99). Another way redemptive suffering may become manifest in chronic illness occurs when people participate in medical studies or trials that may contribute toward improved medical care or cures.

**Social model of understanding illness.**

*So, now instead of being an independently fit person,*

*I'm an independently disabled person (laugh). . .*

*no, chronically ill person who occasionally needs help, you know.*

*It's all relative to the position you're in.*

(A person with RA, quoted in Dubouloz et al., 2004, p. 402)

Multi-dimensional models of understanding illness are relatively recent. In 1997 Engel championed a biopsychosocial model that accounted for the interaction of biological, psychological, and social components of illness (Keefe et al., 2002, p. 641), but he did not include a spiritual component. Today interest in holistic (i.e., integrating mind, body, and spirit) approaches to medical care continues to grow in the United States (Walker et al., 2004, p. 465). These perspectives parallel the development of the multi-dimensional social model of illness and disability.

The social model of understanding disability emerged in the United States in the 1960s (Eiesland, 1994, pp. 53-63). This model works well for chronic illness when these health conditions are also associated with disabilities. The social model understands disability as a variation of “normal,” albeit an experience of normal that is limited by contextual social constructions that lead to unequal treatment based on people’s abilities

(Smart & Smart, 2006, p. 29). Disabilities are interactional with the person's environment; i.e., a person is disabled to the extent that the environment may have caused or exacerbates a physical limitation. Therefore, disabilities are also variable conditions (Jette & Keysor, 2003, p. 118).

*I don't like the way, like, a chronic illness*

*sort of colors your personality to someone else.*

*So, I don't want to be looked at, you know, as someone who has rheumatoid arthritis.*

*I'd rather just be looked at as Darlene.*

(Darlene, a woman with RA, quoted in Dubouloz et al., 2004, p. 401)

The social model builds on precepts of the biomedical model, but it alleviates the onus of personal responsibility for physical limitation and places that responsibility on society. "Treatment' within such a perspective becomes a matter of social restructuring and reorganization rather than personal therapeutic intervention or health education to modify individual behavior" (Pattison, 1989, p. 28). It is important to note that within this understanding society is held responsible for treatment of disabilities, and society is also obligated to define disability and ensure that definitions serve and do not punish individuals. This is a profound perspective shift from the way the biomedical model assigns sole responsibility for causality and cure to individuals with illnesses and disabilities (even though health care providers facilitate curing, the ultimate responsibility lies with the individual to follow protocol, have a positive attitude, etc.). In a similar

manner, the moral model understanding is individualistic regarding responsibility for illness and disability. Although gods or demons may have initially orchestrated the physical malady, it is up to the person with the illness or disability to realize a cure (e.g., by repenting, praying fervently for a miracle, or responding to the pedagogical challenge).

In the future, a more useful variation of the social model may be the recently proposed “affirmation model.” This model has developed, in part, in response to the social model’s lack of accounting for pain and chronic illness not related to disability (Swain & French, 2000, p. 571). However, the affirmation model is not fully developed nor widely accepted within disability studies, and further development of its ideas is beyond the scope of this dissertation. The social model refers to the most salient aspect of chronic illness for this discussion on causation: the contextual and socially constructed nature of illness.

***Social model: Theological implications.***

*The outside world doesn’t seem to be able to grasp that you can look OK on the outside but maybe feel ah . . . washed out on the inside. They can’t see that.*

*I think society on the whole needs to see you missing an eyeball,  
or missing a limb to understand a handicap or disability.*

(A person with RA, quoted in Dubouloz et al., 2004, p. 401)

*Why burn yourself out? Energy’s very precious. . . .*

*You learn that it doesn’t matter if the floor’s not vacuumed . . .*

*In that respect, [RA has] been to my benefit because it's calmed me.*

(A person with RA, quoted in Dubouloz et al., 2004, p. 404)

The social model takes a moral stance that the individual is not to blame for disability. Rather, judgment falls on the collective sin of able-bodied persons who have created and imposed limits on people with mental and physical conditions, limits that often lead to stigmatization and neglect (Pattison, 1989, p. 13; Swain & French, 2000, p. 571). Social model views also impose judgment when they uphold “stereotypes that regard disabilities as signs of weakness, helplessness, and biological inferiority” (Eiesland, 1994, p. 64).

Even as society imposes limits, communities of care also exist within society, and these communities provide a place for people to come together to lament their suffering and to work against oppressive social discourses. When people lament their illness experiences, they engage Nelson’s radical suffering paradigm. Eschatological hope can be found in this model of understanding when God/the transcendent is seen as “the advocate of the oppressed, judge of human cruelty and fellow sufferer” (Nelson, 2003, p. 409, see also Creamer, 2009, p. 86). Advocacy efforts also provide a way for suffering to become a redemptive process for individuals with chronic illness or disability and for their families and support communities.

Generally speaking, the social model is well suited to address certain aspects of chronic and disabling conditions, such as supporting the pragmatic work of addressing

social barriers. However, beyond these efforts at reducing suffering, the social model has little else to say about God/the transcendent or humanity (Creamer, 2009, p. 88).

### **Provisional Constructive Theological Claims about Chronic Illness**

*There is part of it that's genetic, and the other part the doctors don't know . . .*

*There it is, it's bad luck. It'll just be as God wills it, I always say.*

(A woman with lupus, quoted in Taïeb et al., 2010, p. 596)

As I have described, people make meaning of chronic illness experiences by first drawing on their embedded understandings of illness. These understandings carry with them theological implications, which can be illuminated by disability theologies, such as those described by Eiesland and Creamer, and by understandings of suffering, such as Nelson's paradigms.<sup>10</sup> No one particular understanding of chronic illness will help every woman with RA, MS, or lupus sustain well-being or her relationship with God/the transcendent in all illness experiences. Women with these diseases would benefit from complex theological meaning making that helps them negotiate life-enhancing ways of understanding their illness experiences over time.

When illness is in the foreground, certain theological understandings of illness may be more helpful than others. For example, Nelson's radical suffering supports lament when diseases flare up; Eiesland's disabled God provides an image of God with the woman in her suffering. During periods of wellness-in-the-foreground, women may find

---

<sup>10</sup> Within the context of spiritual direction with a particular woman, other theological resources might also be helpful. Eiesland, Creamer, and Nelson offer a starting point for further reflection.

that Creamer's theology of limits helps them accept their illnesses as a normal part of life, or a redemptive suffering view may help some women find hope in their experiences by framing their illnesses as invitations to help others in their suffering.

Recalling the portrayal of a woman's experience with RA, MS, and lupus developed in Chapter Two, and taking into account the importance and substance of meaning making in the context of chronic illness presented in this chapter, I offer the following description of chronic illness: Chronic illness, as experienced by a woman with RA, MS, or lupus, is an ambiguous, liminal experience of healthy/sick and healing/suffering. Chronic illness is characterized by ongoing losses, some of which may be disenfranchised. Suffering, disenfranchised losses, and the ambiguous, liminal nature of these diseases are catalysts for meaning making. When a woman cannot make sense of her illness experiences and sustain a well-integrated spirituality, she is at risk of getting stuck in chronic spiritual struggles that can negatively affect her health and well-being.

I also make the following provisional theological claims about women's experiences of autoimmune disease:

(1) Women with RA, MS, and lupus need complex and flexible theological understandings of autoimmune illness experiences that can account for the full lived reality of the ambiguous nature of these chronic diseases and support life-enhancing relationships with God/the transcendent (e.g., Nelson's ambiguous creation and Creamer's theology of limits).

(2) Women with autoimmune diseases need to engage in ongoing, complex, and contextual theological meaning making, tested through coping strategies and spiritual

practices,<sup>11</sup> in order to establish, restore, and/or maintain well-integrated spiritualities and relationships with God/the transcendent that can bear the weight of the chronic illness experience and prevent women from getting stuck in chronic spiritual struggles.

(3) Particularly when illness is in the foreground, women with autoimmune diseases need to share their experiences of loss and have their losses acknowledged, limiting the potential for disenfranchisement. Spiritual practices that support lament (e.g., Nelson's radical suffering) and meaning making that enables women to sustain relationships with God/the transcendent in the midst of suffering (e.g., Eiesland's disabled God) may help restore a woman's sense of well-being when illness is in the foreground.

(4) When wellness is in the foreground, understandings of God/the transcendent, enacted in coping strategies and spiritual practices, that allow women with autoimmune diseases to construct narratives of hope and find benefits in their illness experiences (e.g., Nelson's eschatological imagination and redemptive suffering views) may help prevent or minimize the duration or effects of chronic spiritual struggles.

These claims propose that women with RA, MS, and lupus need theological understandings that are as complex, contextual, and multi-dimensional as their experiences of chronic illness in order to sustain wellness and their relationships with God/the transcendent over months and years of autoimmune disease. As a corollary, their coping strategies and spiritual practices need to be informed by their theological understandings. They also need to engage in ongoing theological meaning making and

---

<sup>11</sup> I will discuss the linkage between meaning making, coping strategies, and spiritual practices in greater detail in Chapter Five.

the acknowledgment of ongoing losses as they live with incurable degenerative diseases.

The next chapter focuses on identifying a caregiving approach that addresses these psychospiritual needs.



#### **Chapter Four: Psychospiritual Care for Women with RA, MS, and Lupus**

In Chapters Two and Three I asserted that appropriate psychospiritual care for women who have RA, MS, and lupus could help them sustain relationships with God/the transcendent and diminish the likelihood of chronic spiritual struggles with the potential to negatively affect health and well-being. Chapter Three's provisional theological claims about a woman's experience of autoimmune disease suggest that an appropriate approach to care for women with autoimmune diseases should take place within an ongoing long-term (over the course of years) relationship, facilitate healing within the context of a woman's relationship with God/the transcendent through complex contextual theological meaning making enacted in coping strategies and spiritual practices, and provide ongoing opportunities for lament and acknowledgment of losses. The current chapter begins by examining the potential for women to find the care they need within the contexts of biomedicine, psychological counseling, pastoral care and counseling, and chaplaincy care.

As my evaluation reveals, none of these contexts addresses all elements of optimal care identified in Chapter Three. As an alternative to these approaches, I introduce a contemporary model of spiritual direction as a unique, long-term, intercultural, approach to care for the psychospiritual needs of women who have autoimmune diseases. I conclude the chapter by describing spiritual direction as a narrative, contextual, and collaborative caregiving practice that focuses on how a

woman's relationship with God/the transcendent is formed and informed by her illness experiences. In Chapter Five, I will elaborate a model of spiritual direction specifically for women with RA, MS, and lupus.

Although I assert that a spiritually-explicit caregiving approach would benefit women with autoimmune diseases, if they are not interested and willing to engage in spiritual care, the point is moot. However, people in general desire spiritual care when they are sick, and two-thirds of patients want physicians to be aware of their religious and spiritual beliefs (MacLean et al., 2003, p. 38). A number of short-term spiritual care approaches have been documented in medical studies with patients who have chronic conditions (primarily with people who have cancer). These studies conclude that patients want spiritual care to continue after spiritual support activities end (e.g., Cole & Pargament, 1999a; Levy & Chan, 2006).

Women, more so than men, rely on religious and spiritual strategies to cope with stress, including illness (Pargament, 1997, p. 143). People with chronic illnesses in general and women specifically are also more likely to use complementary therapies to supplement biomedical care for health problems, a tendency that may reflect their desire to align care practices with personal beliefs that value holistic approaches to care (Brannon & Feist, 2010, p. 205). A study with people who have rheumatoid arthritis shows that women with RA rely more than men with RA in daily coping strategies that include lament, meaning making, and finding "spiritual comfort" as part of living with their disease condition (Keefe et al., 2002, p. 646). Given the need for spiritual care for women with autoimmune diseases, as well as the desire and willingness demonstrated by

women with chronic health conditions to engage spiritual coping strategies and participate in complementary care approaches, the question becomes: What is the best context for spiritual care for women with RA, MS, and lupus?

### **Evaluation of Three Approaches to Care**

In the following sections, I evaluate the potential for biomedical, psychological, and pastoral caregivers to address the psychospiritual needs of women who have RA, MS, and lupus. These evaluations are necessarily brief, focusing on the potential for long-term (over the course of years) relationships between caregivers and careseekers, opportunities for lament and acknowledgment of ongoing losses, and facilitation of complex theological meaning making. Characterizations of caregivers in this dissertation represent the type of care most women with RA, MS, and lupus would likely encounter within each context. Individual providers may differ in any number of ways from these generalized descriptions.

#### **Evaluation of biomedical care.**

Primary care physicians, rheumatologists, neurologists, and nurses often have long-term caregiving relationships with women who have RA, MS, and lupus. Because autoimmune conditions require constant monitoring, these care providers spend time with their patients over the course of years, during periods of wellness-in-the-foreground as well as illness-in-the-foreground. However, in spite of the fact that nurses and physicians have long expressed their commitment to the overall well-being of their patients,

numerous studies and commentaries indicate that the spiritual dimension of illness is often neglected in biomedical health care (e.g., Badaracco, 2007, pp. 120-121; M. H. Cohen, 2006, pp. 126-127; Dale & Hunt, 2008, pp. 713, 716; A. Edwards et al., 2010, p. 13; Ellis & Campbell, 2004, p. 1161; Handzo & Koenig, 2004, p. 1242; Hebert, Jenckes, Ford, O'Connor, & Cooper, 2001, p. 685; Koenig et al., 2001, pp. 2-5; Puchalski, 2006b; Rowe & Allen, 2004, p. 62; Strunk, 2004, pp. 293-294; Whittemore & Dixon, 2008, pp. 185-186).

A significant barrier to medical care that consistently addresses spiritual dimensions of the person is the complex relationship between medical professionals and the insurance companies that dictate many aspects of medical practice. Insurance reimbursement constraints reinforce a biomedical culture that emphasizes curing, pathophysiology, the use of medical technology, and expedited patient visits (e.g., Laine, 2002; Verghese, 2011). Medical professionals who consider a patient's spiritual dimension often only do so in end-of-life situations (Luckhaupt et al., 2005). Although there is growing interest in holistic and integrative care, generally speaking, the culture of biomedicine devalues spirituality, making it an inhospitable context for theological meaning making. Biomedicine is also not an optimal setting for ongoing lament and acknowledgement of losses. Although women with RA, MS, and lupus may share losses associated with autoimmune conditions, medical care providers may disregard or minimize patient experiences in ways that disenfranchise losses (as described in Chapter Two).

When physicians are asked who should provide spiritual care to patients, answers range from limiting spiritual care to specially-trained providers to asking physicians and nurses to integrate spiritual care into their diagnostic and treatment protocols to utilizing multi-disciplinary teams to address different dimensions of patient care (A. Edwards et al., 2010, p. 13; Kliewer, 2004; Puchalski et al., 2009). Some critics of integrating spiritual care into the biomedicine model suggest that integration would cross boundaries that protect patients from malpractice by practitioners in both medicine and religion/spirituality (M. H. Cohen, 2006, pp. 126-127; Kliewer, 2004, p. 621). Arguably the most cited article opposing the physician-as-spiritual-caregiver model was authored by Sloan, Bagiella, and Powell (1999). Their viewpoint is summarized thusly:

When doctors depart from areas of established expertise to promote a non-medical agenda, they abuse their status as professionals. . . . There is an important difference between “taking into account” marital, financial, or religious factors and “taking them on” as the objects of interventions. (pp. 666-667)

The notion of spiritual malpractice points to another barrier to providing adequate spiritual care for women with RA, MS, or lupus: caregiver authenticity. Capable care for the spiritual dimension of women with autoimmune conditions (i.e., care that extends to complex theological meaning making enacted in coping strategies and spiritual practices) is grounded in the authentic spirituality of the caregiver. Research shows that physicians and medical residents who identify themselves as religious/spiritual are indeed more likely to integrate spirituality into their medical care practices (Curlin, Chin, Sellergren, Roach, & Lantos, 2006, p. 446; Luckhaupt et al., 2005, p. 560). Spirituality in medicine is typically reflected in practices of compassionate care (e.g., attentive listening) or “spiritual assessments” in which health care providers ask patients a brief series of

questions about their religious/spiritual preferences and concerns (Pembroke, 2008, p. 555). Courses in spirituality for physicians and nurses (e.g., in medical school, nursing school, or through continuing education opportunities) help integrate spiritual care into the biomedical model (Puchalski, 2006a). However, few health care professionals develop expertise and personally invest in spiritual care practices at a depth that prepares them to offer the kind of ongoing psychospiritual care needed by women who have autoimmune diseases (Egnew, 2005). For some health care professionals, the skills and/or gifts necessary for intuitive and highly contextualized approaches to spiritual care may be too far removed from the skills needed to effectively provide evidence-based, standardized medical care.

As well-intentioned as recently proposed spiritual care practices may be (e.g., taking a spiritual assessment), authentic care for a patient's spiritual dimension is not something physicians and nurses can adequately address through questions on a checklist. In fact, one study indicates that many patients can identify physicians likely to engage in spiritual care "as early as 'when [the physicians] enter the room'" (Ellis & Campbell, 2004, p. 1161). This finding underscores the importance of the therapeutic relationship in facilitating healing (i.e., caregivers must be perceived as credible, authentic facilitators of spiritual healing, not simply administrators of spiritual protocol).

Credible and knowledgeable caregivers are also a concern with disease-focused support groups, which are frequently offered for people with chronic conditions. Although support groups can provide a safe place for lament, they typically do not focus on spiritual concerns (e.g., Arthritis Foundation support groups focus on improving

physical function). When spirituality is addressed, support group facilitators—who are often lay volunteers with the disease—would not typically be able to facilitate complex meaning making.

It is realistic to expect that some health care providers will actively integrate spiritual care into their medical practices, but multiple barriers prevent the full integration of even routine spiritual care, such as taking spiritual histories and assessing the need for a spiritual care referral. The reality of biomedical care in the U.S. today is that physicians and nurses—who are often seen as the default spiritual caregivers in the health care context—are typically not eager, available, or adequately prepared to provide women with RA, MS, and lupus with long-term psychospiritual care that includes complex theological meaning making, attention to spiritual coping and practices, and ongoing acknowledgment of losses. Biomedical care does remain, however, a critical component of a holistic plan of care for women with RA, MS, and lupus.

As noted, women are generally open to supplementing biomedical care with other treatment options (Becker, 1999, p. 162). As many as 79 percent of people who supplement biomedical care with other modalities believe that the combination of biomedical care and a complementary therapy is “superior to either one alone” (Eisenberg et al., 2001). Many lupus patients, nearly half of all people with rheumatoid arthritis, and the majority of people with MS engage in at least one complementary therapy to cope with their disease (Astin, Beckner, Soeken, Hochberg, & Berman, 2002, p. 291; Haija & Schulz, 2011, p. 47; Stuifbergen & Harrison, 2003, p. 147). Multiple sclerosis patients have affirmed that many use complementary modalities specifically to

achieve holistic care that includes the spiritual dimension (Nayak, Matheis, Schoenberger, & Shiflett, 2002, p. 181). In this dissertation, psychotherapy, pastoral care, and spiritual care<sup>1</sup> are considered complementary approaches to biomedical care.

### **Evaluation of psychological care.**

Mental health providers recognize value in augmenting biomedical care to address psychological concerns for people with chronic illnesses in general and for women with autoimmune diseases in particular (e.g., Astin et al., 2002, p. 301; Dixon, Keefe, Scipio, Perri, & Abernethy, 2007, p. 248). However, psychotherapy remains a “nonspiritual tradition” (Bolletino, 2001, p. 104) where the majority of caregivers do not explicitly address the spiritual dimension in patient care. Only recently have a handful of psychologists and psychiatrists emphasized spirituality in mental health care—notably Koenig (e.g., 2002b), Pargament (e.g., 2007), Sperry (2005), and Shafranske (2005).

The psychotherapeutic community’s lack of focus on the spiritual dimension of health suggests that most psychological caregivers are “theologically naïve” (Doehring, 2009, p. 7). Theologically naïve therapists are inclined to make simplistic and/or inaccurate assumptions about their clients’ religious and spiritual beliefs and practices in ways that disregard the unique qualities of the client’s spiritual orienting system. Failure to attend to the contextual nature of spirituality diminishes the ability of psychotherapists

---

<sup>1</sup> Spiritual direction, prayer, meditation, and other spiritual practices are considered mind-body interventions, one of five primary categories of complementary treatments, as defined by the National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health (“What is complementary and alternative medicine?,” 2010).



to facilitate complex theological meaning making with their clients. In addition, therapist reliance on manualized treatment protocols, which are frequently used within the psychotherapeutic context, increases the likelihood that therapists would treat religious and spiritual practices and coping strategies as mere prescriptive tools (Pargament, 2007, pp. 176-177). Lack of caregiver authenticity is a concern in the psychotherapeutic context.

Time is another limitation of psychotherapeutic care for women with RA, MS, or lupus. Even spiritually-oriented psychotherapy is usually short-term care (e.g., 6-10 weeks). Women who work with a spiritually-integrated psychotherapist may find that the psychotherapeutic focus on problem-solving means that during periods of wellness-in-the-foreground—when women may be more amenable to meaning-making and benefit finding—these women are not actively engaged in a psychological caregiving relationship that supports this spiritual work. Although the confidential psychological caregiving relationship provides a safe space to lament losses, until spiritually-oriented psychotherapeutic approaches are more common and more theologically sophisticated, and caregivers routinely offer long-term care both in times of illness-in-the-foreground and in times of wellness-in-the-foreground, psychological care does not offer women with autoimmune conditions the type of long-term spiritual care they need.

### **Evaluation of pastoral approaches to care.**

In this dissertation, pastoral care refers to care provided by representatives of faith communities. As noted in Chapter One, some pastoral caregivers now prefer the term

*spiritual care* to describe their ministry. I will use *pastoral care* in this chapter to differentiate particular categories of caregivers—clergy, pastoral counselors, and chaplains—from the broader community of spiritual caregivers, which includes spiritual directors.

Although people often think of pastoral care providers as clergy,<sup>2</sup> today laypersons supplement clergy care on a regular basis in many faith communities. Lay caregivers often provide care during crises, and they also support people in the grieving process. These relationships are relatively short-term and problem-focused. For example, Stephen Ministries is a national organization that helps Christian communities train lay people to provide one-on-one care ("What is the difference between a Stephen Ministry relationship and a friendship?," 2011). In their training program, Stephen Ministries instructs lay care providers to establish clear caregiving boundaries that do not extend into times of wellness (although friendships may continue after formal caregiving relationships end).

Pastoral care relationships with clergy are confidential contexts in which people can safely lament losses and engage in theological meaning making. The primary barriers to providing the type of care needed by women with autoimmune diseases are time and theological constraints that may be imposed by particular religious institutions.

Clergy charged with leading faith communities often provide pastoral care as one responsibility among many. Many clergy also have ceremonial, liturgical, administrative, educational, and/or formational commitments to their faith community. As a result,

---

<sup>2</sup> I use the term *clergy* to refer to ordained or authorized representatives of faith traditions, including but not limited to pastors, priests, clerics, imams, mufti, ministers, and rabbis.

clergy-provided pastoral care is typically short-term (e.g., 1-6 visits) crisis-oriented care (Vander Zee, 2002, p. 181), and this constraint is specified in some denominational ministerial codes of conduct. Clergy may refer community members with long-term needs to counseling professionals (in the case of psychological concerns) or to spiritual directors (for long-term spiritual guidance).

Some religious institutions may enforce theological constraints on meaning making that make it difficult or impossible for pastoral caregivers to use an intercultural approach to care. In these situations, clergy assume a shared understanding of religious/spiritual beliefs which could render meaning making either unnecessary (from the perspective of the caregiver) or only meaningful for women immersed in that particular belief system. For example, a religious community might understand physical disease to be an outward sign of spiritual sickness. Caregivers in such a community would expect ill careseekers to ask for forgiveness for their sins and seek healing through a restored relationship with God. Caregivers would not engage careseeker understandings that attribute the cause of their illness to genetic predisposition or to a random act of nature. Such beliefs might be considered naïve or even heretical. If a careseeker in this community shared the moral understanding that illness requires purification from sin, meaning making would be deemed unnecessary; caregiver and careseeker would simply proceed with the appropriate actions to remedy the careseeker's condition.

Some faith communities provide grief and loss support groups as part their pastoral care ministry. These groups often focus on topics such as divorce, miscarriage, death, job loss, and cancer. Unless a group addresses chronic illness, women with RA,

MS, and lupus may not find an appropriate place for lament and meaning making related to their conditions. In fact, women with autoimmune diseases might present an unwelcome or intrusive presence to a group dedicated to other concerns. Support groups that address chronic illness—particularly autoimmune diseases—and establish adequate levels of trust and confidentiality could provide a safe place for lament. However, the potential for long-term, complex theological meaning making and attention to spiritual practices would depend on the capabilities and limits of authority granted to group facilitators.

Pastoral care also includes the specialized ministries of pastoral counseling and chaplaincy care. Pastoral counselors are trained and certified mental health professionals with extensive theological education that allows them to integrate these two disciplines in an explicitly religious/spiritual context. Pastoral counselors may be affiliated with faith communities, counseling centers, or other caregiving agencies. Many pastoral counselors are ordained clergy. Pastoral counselors are trained within a therapeutic culture that focuses on problems associated with a person's psyche, most typically within the context of crisis care (Hamilton-Poore & Sullender, 2009, p. 30). Although there is potential for relatively long-term pastoral counseling relationships, most relationships last eight weeks on average and are crisis oriented (L. Townsend, 2009, p. 116). Although pastoral counselors provide a safe place for lament throughout the duration of the care relationship, and pastoral counselors may also help people attend to their spiritual lives, this care relationship does not provide an ideal context for ongoing lament or meaning

making in recurrent vacillations between illness-in-the-foreground and wellness-in-the-foreground perspectives.

Long-term pastoral counseling usually uses psychodynamic personality theories that focus on the way the therapeutic relationship re-enacts early childhood relationships. Change becomes possible when women re-experience and work through the needs and conflicts of their childhood relationships through the transference of these relationships onto the therapeutic relationship (Cooper-White, 2004). In spiritual direction, change depends on what happens in a woman's long-term relationship with God/the transcendent, not on her relationship with her spiritual director, although a positive alliance and trusting relationship with her director needs to be established at the beginning of their practice together.

Chaplains are theologically educated pastoral caregivers from a diversity of religious traditions; they may be ordained clergy or lay leaders. Chaplains typically work within institutional settings, particularly hospitals, hospice, and the military. Most chaplains are authorized by people within their faith tradition who oversee this religious vocation (i.e., an endorsing body), although chaplains often care for people of diverse religious backgrounds. Chaplains are required to demonstrate competence with intercultural or interreligious approaches to care. Because the chaplaincy profession grew out of a desire to "break down the dividing wall between religion and medicine" (Leas & Thomas, 2008), chaplains are often well-equipped to support lament and theological meaning making with women who have autoimmune conditions. Within hospice settings they often facilitate such spiritual work with patients as they approach the end of their

lives. However, in a hospital context, chaplaincy work is more typically acute crisis management with a limited number of visits with each patient (often only one visit). Given that RA, MS, and lupus do not ordinarily require hospitalization (hospital stays for this population are short-term crisis events or unrelated to these disease conditions), access to chaplaincy care is limited until chaplain-provided, long-term, outpatient spiritual care is widely available.

My evaluation of contexts of care for women with RA, MS, and lupus finds biomedical, psychotherapeutic, and pastoral approaches inadequate to address the unique psychospiritual needs of these women through years of illness experiences. Inadequacies stem from one or more of the following concerns: caregivers lack the desire, ability, or spiritual authenticity to facilitate complex theological meaning making; careseekers could not safely lament ongoing losses (especially spiritual losses); and the lifespan of a typical caregiving relationship is too short for women with recurring needs over the course of years. Spiritual direction, however, can support long-term care relationships, and it can provide a context for complex theological meaning making, lament, and acknowledgement of disenfranchised (or potentially disenfranchised) losses for women with RA, MS, and lupus.

### **Spiritual Direction as an Approach to Care**

I personally rely on the ongoing relationships I have with both medical health care professionals and my spiritual director to help me sustain well-being in the midst of chronic illness. I collaborate with my rheumatologist and the nurses in her practice to

address my physical issues; my spiritual director and I collaborate with God/the transcendent on care for my psychospiritual needs. The following story, published in the on-line monthly “Membership Moments” of Spiritual Directors International (Karp, 2010), illustrates how other women with autoimmune diseases might describe their experiences of spiritual direction as a complement to biomedical care:

*By the time I was in my mid 40's, I had established a career in Clinical Social Work; was comfortable with God and my faith of Quakerism; was married to my college sweetheart -- with a beautiful home, two fine boys, a Golden Retriever, and even two cars! I was set.*

*Then, in one dramatic 24-hour period, it all began to unravel. Within a short span of time, I was diagnosed first with Lupus SLE then with Parkinson's: two life threatening, chronic diseases. At first, I tried to manage the chaos that the Lupus brought to our lives, all on my own. Within a short time, however, I was driven to the use of drugs and psychiatry for depression when, two years into the diagnosis, the Lupus inflamed my kidneys and my very life was suddenly on the line. It was after stabilizing on an experimental chemotherapy, that I stumbled across 'Spiritual Direction' and knew instinctively and immediately that that was my door to sanity, even as I had no idea what spiritual direction really was. In that critical moment, I knew only that I was exhausted, and that therapy could not touch the pain I was in – it was spiritual. I was spinning helplessly – in increasingly tight circles – desperate for relief from relentless questions:*

*WHERE WAS GOD?*

*WHAT HAD I DONE TO DESERVE THIS?!*

*HOW COULD I LIVE WITH THIS MEDICAL NIGHTMARE?*

*MY FAMILY SHOULD NOT HAVE TO LIVE WITH THIS LEVEL OF CHAOS AND LOSS –*

*IT IS NOT FAIR!!*

*WHY ME?!*

*GOD HAS BETRAYED ME!!*

*Spiritual direction has done nothing short of quieting me down, helping me to grow up and into my new reality, creating a container for my fears and extreme panic, and bringing me home to myself and my God. Spiritual direction has transformed my life to one of possibilities out of my now deepened and renewed relationship with the God-of-my-understanding.*

I use this woman's story as a case study throughout the remainder of the dissertation to illustrate the proposed model of spiritual direction. I call the woman Mary. Only the information presented by the original author in the "Membership Moments" posting (as seen above in its entirety) is factual; all other details have been fabricated for illustration purposes, including details about Mary's spiritual director Jane, conversations between Mary and Jane, and descriptions of Mary's spiritual life and her experiences of chronic illness.

### **The practice of spiritual direction in the Christian tradition.**

People have sought spiritual guidance from one another for centuries. Spiritual guidance, spiritual companionship, and spiritual direction are but a few names for the practice of seeking help with or insight into one's relationship with God/the transcendent. Although contemporary practitioners use a variety of terms, the most common referent remains *spiritual direction*, which I use in this dissertation. In the description of spiritual direction that follows in this chapter and in Chapter Five, I refer to both the historical Christian tradition<sup>3</sup> and to the contemporary practice of spiritual direction. The discipline is as firmly rooted in history as it is flexible for the needs of careseekers today.

Within the Christian tradition, the roots of spiritual direction are evident in the relationships among Jesus and his disciples and in spiritual mentoring relationships among religious leaders in the early years of the Christian Church. Eventually, spiritual

---

<sup>3</sup> This dissertation briefly describes the history of Christian spiritual direction. Additional historical information can be found in a number of classic texts (e.g., Barry & Connolly, 1982; T. Edwards, 1980, 2001; Leech, 2001).



direction became a more common practice among lay and religious alike, modeled after the practices of the Desert Fathers and Mothers.<sup>4</sup> After Roman Emperor Constantine I legalized Christianity in the fourth century, Christians could no longer be martyred for their faith. Although Christians obviously benefitted from this decree, they also lost a public way to demonstrate deep commitment to their faith. As an alternative to martyrdom, some Christians followed in the footsteps of ascetics and moved to isolated desert locations where they could practice poverty, solitude, fasting, meditation, prayer, and other spiritual disciplines. Some of these “spiritual athletes,” such as Abba Antony, become legendary, and soon other Christians began making pilgrimages to remote sites to seek the counsel of these desert sages (Waddell, 1998).

Consultations with the Desert Fathers and Mothers focused on the careseeker’s relationship with God and on his or her spiritual practices. Spiritual guidance was characterized by silence, prayer, contemplation,<sup>5</sup> and discernment (e.g., Cassian, trans. 1997), which remain the core elements of spiritual direction today. Over the centuries a number of monastics formalized spiritual direction practices to reflect the spiritualities that developed within their particular religious communities (Byrne, 1990). Monastic spiritual direction traditions, such as Benedictine (e.g., Chittister, 2003) and Ignatian (e.g., Loyola, trans. 2000) spiritual direction, are still practiced today. Generally

---

<sup>4</sup> Desert Fathers and Mothers are also frequently referred to as Desert Abbas and Ammas.

<sup>5</sup> Contemplative practices, such as prayer and spiritual direction are characterized by silence and a posture of listening to or being available to God/the transcendent. Interestingly, “medical professionals have long recognized that silence plays an important role in healing. Bed rest, for example, is the usual prescription for many illnesses, from the common cold to myocardial infarction. The more ill you are, the more your doctor will insist that you be quiet and rest. But despite this age-old appreciation of the value of silence, medical and psychological researchers and practitioners until recently paid scant attention to states of *internal silence*” (Bloomfield, 1989), such as those cultivated in contemplative practices.

speaking, the practice of Christian spiritual direction has changed little over the centuries, albeit it has been enriched by modern psychological understandings of human behavior that help illuminate a person's relationship with God/the transcendent. Today, spiritual direction remains a familiar practice within the Catholic, Eastern Orthodox, and Anglican traditions, and interest has been growing among other Christians as well as with people who consider themselves "spiritual but not religious" (Hamilton-Poore & Sullender, 2009, pp. 26-27; Vest, 2003).<sup>6</sup>

History might suggest that spiritual direction is best suited for elite spiritual practitioners. For example, people who immerse themselves in deep contemplative practices, exemplified by the anonymous fourteenth-century author of *The Cloud of Unknowing* (trans. 1981); report mystical experiences in the manner of John of the Cross (trans. 1959), Teresa of Ávila (trans. 1961), or Evelyn Underhill (2005/1930); or engage in ascetic practices that glorify suffering, like some Desert Fathers and Mothers (Waddell, 1998). While extreme practices and experiences have been highlighted in the historical accounts, contemporary writings depict spiritual direction as a safe, practical, and meaningful practice for a diverse population of directees with unique spiritual histories, temperaments, and desires (Vest, 2000, 2003; Wagner, 2006).

Contemporary Christian spiritual direction<sup>7</sup> is a contemplative practice of spiritual care in which at least two people meet regularly—typically once per month for an hour,

---

<sup>6</sup> Adherents of other religious traditions (e.g., Buddhism, Islam, and Judaism) also practice spiritual direction in forms resonant with their belief systems.

<sup>7</sup> This dissertation provides an overview of contemporary Christian spiritual direction. Additional information can be found in a number of classic texts (e.g., Barry & Connolly, 1982; T. Edwards, 1980, 2001; Guenther, 1992; Hart, 2007; Leech, 2001; Ruffing, 2000).

often over the course of years—to focus on a person’s relationship with God/the transcendent. This primary focus on God/the transcendent is what sets spiritual direction apart from other approaches to spiritual care.<sup>8</sup> In traditional Christian language, the caregiver in a spiritual direction relationship is referred to as the spiritual *director*, and the careseeker is called the *directee*. In a group spiritual direction model, all members of the group may function as directors as the focus of contemplative discernment within the group moves from one directee to another.

Although the term *direction* may suggest an authoritarian or master-disciple relationship between director and directee, God/the transcendent is explicitly understood to be the ultimate director. In spiritual direction, director and directee collaborate with each other and with God/the transcendent through contemplative listening and discernment practices. This collaborative work is encapsulated in the traditional questions of spiritual direction: Where is God in this? and What might God be calling you to do in response? Although these questions remain constant from session to session, director and directee engage in ongoing, contextual, constructive, theological meaning making in order to respond to the questions. In this meaning making process, director and directee seek to articulate—over and over again—how the directee understands God/the transcendent (e.g., loving, punitive, present in suffering, distant), how she understands the movement of God/the transcendent in her life (e.g., presenting an opportunity for the directee’s growth, calling the directee to take action, communicating a message to the directee), and how she will respond to God/the transcendent *at this time* (e.g., accept the

---

<sup>8</sup> See the Appendix for a more detailed comparison of spiritual direction to other spiritual care approaches.

job offer in Minneapolis, try a new prayer practice, reconcile with her mother, reflect on her need to be in control).

Relational dynamics with spiritual direction are markedly different than clinically-oriented expert-patient relationships between other health care providers and patients/clients. Spiritual directors seek to modify power differentials traditionally found in health care through intentionally collaborative relationships in which directors disclose a degree of transparency and vulnerability while maintaining the focus of care on the directee (Guenther, 1992, p. 46). Rather than being disengaged experts, spiritual directors monitor an appropriate level of give and take in the spiritual direction relationship, espousing what some describe as a feminist commitment to attending to power within caregiving relationships (Fischer, 1988, p. 6). The more reciprocal and less hierarchical nature of the spiritual guidance relationship is so critical to contemporary practice that many spiritual directors prefer to be called *spiritual companions* or *spiritual friends* to more clearly characterize their approach to care.

Directees always initiate spiritual direction, and they do so by inviting another person to companion them on their spiritual journeys. Directors may decline an invitation, but they do not initiate spiritual direction relationships. Both participants are accountable to the contract of care, which includes where and when to meet, how often and how long to meet, whether or not pay or donations are expected/accepted, confidentiality, and acceptable means/frequency of contact between sessions. Either participant may determine when it is time to end the relationship.

Spiritual directors may be clergy or laypersons; the latter may or may not be associated with particular faith communities. Directors and directees typically meet in private, quiet locations conducive to intimate conversation, such as the director's home, a private room in a business location (including prisons), a church, or an outdoor venue. Spiritual direction is a flexible and highly portable form of spiritual care. I initiated a relationship with my spiritual director when I lived in Tulsa and found out I was moving to Memphis, where she was located. We got to know each other through phone conversations. After I moved to Memphis, we worked together in person for over two years. When I moved from Memphis to Denver, we agreed to continue monthly spiritual direction sessions by phone, and we have continued the relationship in this way for nearly six years. As a spiritual director, I have also offered spiritual guidance via e-mail.<sup>9</sup>

Some people become spiritual directors by virtue of ordination or a formal commitment to religious orders. The process of becoming ordained or a member of a religious order often includes spiritual direction to clarify one's call, as well as education in offering spiritual guidance to others. Many, if not most, lay directors discover that they are gifted as "holy listeners" when they recognize that they are consistently sought out for spiritual guidance by other people. Some directors seek historical grounding, skills training, and supervision in spiritual direction formation programs, although this education is not required to identify oneself as a spiritual director.<sup>10</sup>

---

<sup>9</sup> Throughout history, Christian spiritual direction has often taken place through letter-writing. For example, the apostle Paul, Ignatius of Loyola, Martin Luther, John Wesley, Frances de Sales, Frederick von Hügel, and Evelyn Underhill have maintained long-term spiritual direction relationships through letters (Arora, 2005). In some cases, letters were the only form of contact between director and directee.

<sup>10</sup> Spiritual direction is not a professional practice that requires licensure, credentialing, continuing education, or guidance from advanced practitioners. That said, thousands of spiritual directors across the

Although spiritual direction is relationship-oriented and not problem-focused, spiritual companions consider the movement of God/the transcendent in all aspects of a person's life, including the struggles. In Mary's case, her struggles with lupus include questions about God's role in the onset of her illnesses and her own culpability (Where was God? What had I done to deserve this?! Why me?!). Mary and her spiritual director would explore such meaning making questions as they arose over time, and they would continue to observe how the disease and Mary's ability to cope with illness affected her life, her spirituality, and her relationship with God/the transcendent.

Spiritual directors are aware that struggles are often multi-dimensional, and they have actively incorporated contemporary psychological understandings of human behavior into the practice of care for decades. Current spiritual direction educational materials (e.g., formation programs, books, journal articles, and educational workshops and events) cover warning signs of deeper psychological issues and encourage spiritual directors to refer careseekers to other helping professionals as needed. Directors need not assume careseekers are in ideal psychological health before beginning spiritual direction relationships (e.g., Barry & Connolly, 1982, p. 71). As a Clinical Social Worker, Mary is aware of a variety of resources to help her cope with her health concerns. She has seen a

---

globe voluntarily participate in formation and certification programs, continuing education, peer supervision, and personal spiritual direction. Certification programs offer "certificates of completion" but do not convey "professional" status. Some spiritual directors accept payment or offerings for their services, carry liability insurance, and/or market their services, but many directors would simply describe their practice as ministry. The worldwide organizing body for spiritual directors, Spiritual Directors International (SDI), serves as a "network and learning community" ("The vision of Spiritual Directors International," 2011). SDI does not provide or oversee certification programs, but they have published ethical guidelines for spiritual direction practice. SDI promotes the practice of spiritual direction, plans pilgrimages to sacred sites around the globe, publishes a peer-reviewed journal as well as books written by and for spiritual directors, and hosts an annual conference to facilitate sharing within the spiritual direction community. More information about SDI can be found at [www.sdiworld.org](http://www.sdiworld.org).

psychiatrist for treatment of depression, but this caregiving relationship has not addressed the spiritual dimensions of her depression or her life with chronic health conditions. Mary collaborates with her spiritual director to discover how her illnesses affect and are affected by her sense of well-being and her relationship with God/the transcendent. Mary and Jane also continuously work together and seek guidance from God/the transcendent to help Mary conserve life-enhancing and transform life-limiting coping strategies and spiritual practices as her needs change with time.

During a spiritual direction session, the director facilitates discernment of spiritual guidance through shared “listening”<sup>11</sup> to God/the transcendent in silence and prayerful reflection. The director’s particular role is to listen with and on behalf of the directee to help discern how God/the transcendent is present and active in the directee’s life. For example, a session between Mary and Jane might begin with the lighting of a candle, several moments of silence and/or a brief prayer offered by one of the women (the session might end in a similar manner). The prayer might acknowledge the presence of God/the transcendent and asks for divine/universal guidance in their time together. Mary would typically share what has been happening in her life since their last session. As Mary’s story unfolds, the women frequently pause in silence to consider what has been said and to “listen” for God/the transcendent. Jane might ask clarifying questions about Mary’s story. If Mary brings a meaning making question to the spiritual direction session (e.g., What have I done to deserve this?), the women would explore how Mary’s images and understandings of God/the transcendent contribute to or offer healing from her sense

---

<sup>11</sup> *Listening* should be understood as an intuitive process more so than an auditory experience, although the latter is also possible.

of responsibility for her illness. Among other considerations, the women would reflect on the life-enhancing or life-limiting nature of such a belief, and they would listen for what God/the transcendent might want Mary to understand about the nature of illness and living with an incurable disease.

Directors may also offer guidance on spiritual practices, or they may simply be present with the directee in times of struggles or confusion. Sometimes, director and directee spend more time together in silence than they do speaking, but the session remains focused on the story of the directee's spiritual life as it relates to God/the transcendent and on theological meaning making needed to respond to God/the transcendent at that time. For example, Mary's director might listen compassionately as Mary describes the pain and uncertainty of living with lupus. Jane might ask Mary to describe spiritual practices that are currently helping her cope with her chronic condition (e.g., listening to soothing music when her pain is intense), and together the women would consider how to transform or replace practices that no longer help Mary. For example, Mary and Jane might discern that participating in a spiritual formation group is life-enhancing for Mary because it helps her feel supported by God/the transcendent, directly and through the relationships she has with other people in the group. However, Mary's current group meets so late in the evening that she gets to bed later than usual and is often exhausted the next day. Mary decides she needs to leave the evening group and join a group that meets during the morning when Mary has more energy.

Spiritual directors often ask a lot of questions, prompting the directee's reflection during and after their session together. Directees make the decisions that affect their



lives. Directors help directees consider the ramifications of their decisions in the context of their relationship with God/the transcendent, and directors facilitate complex theological meaning making as part of directee's discernment process with God/the transcendent.

***Group spiritual direction.***

Spiritual direction can take place in one-on-one relationships, as I have illustrated with Mary and Jane, or in a group format. Group spiritual direction is similar to one-on-one direction in most respects (i.e., participants honor a contract of care and engage in narrative practices, contemplative reflection, and discernment).<sup>12</sup> Sometimes spiritual direction groups form on an ad hoc basis (e.g., in a retreat setting), but they are generally made up of an established group of three to five people committed to companionship each other over an extended period of time. Group sessions may extend to two or three hours to allow each participant to be the center of contemplative attention and discernment. The group's director may choose to only facilitate the session, or s/he may choose to also take a turn as directee. All members of the group participate in listening for and with each other.

Group models of care are particularly attractive to women, perhaps because group dynamics reinforce the collaborative relational dimension of a woman's well-being (Fischer, 1988, p. 21; see also Barry & Connolly, 1982, p. 117). Group spiritual direction exemplifies the pastoral theological paradigm of *communal contextual care* in which a

---

<sup>12</sup> I recommend Dougherty's (1995) classic text on group spiritual direction for readers interested in a detailed description of this practice.

community of faith is the primary context for the “care of persons, care of worlds” (L. K. Graham, 1992). Communal contextual care is grounded in liberation and feminist theologies that call people of faith to bring about relational justice through healing, sustaining, resisting, transforming, and liberating practices (Patton, 1993). The communal contextual paradigm extends understandings of careseekers as isolated “living human documents” to envisioning careseekers embedded within a “living human web” (Miller-McLemore, 1996). The web metaphor more accurately depicts the complexity of individual experiences mediated through relationships with other persons, the world, and God/the transcendent. In the case of group spiritual direction, care encourages relational development while still recognizing the unique and diverse relationships and views of God/the transcendent operating within and among the women in the group. The spiritual director in a group setting carefully attends to this balance.

There are a number of ways in which women with RA, MS, and lupus would benefit from group spiritual direction. First, groups of all kinds provide social support, and social support is associated with greater well-being (Koenig et al., 2001, p. 100). The positive effects of social support may be enhanced when women with autoimmune disorders—women who often feel isolated by their health conditions—form a community with women who share similar illness experiences. Being with other women who have chronic health conditions also appears to positively influence a woman’s ability to shift to or sustain a wellness-in-the-foreground perspective (Paterson, 2001, p. 24). Additionally, a larger community of witnesses and contributors magnifies the transformative power of practices such as discernment, meaning making, ritual, and the acknowledgment of losses

(Barry & Connolly, 1982, p. 117; Berry, 2009, p. 198; Hogue, 2003, p. 141; Maggio, 2007, p. 578; Pesek, 2002, pp. 132-133).

Women participating in group spiritual direction would also have an opportunity to form reciprocal relationships of intercultural care. Spiritual directors would need to teach, model, and facilitate the practice of intercultural care in a group to ensure that participants resisted the tendency to impose their own beliefs on others. As women learned how to step into each other's spiritual worlds—shaped in unique ways by illness experiences and relationships with God/the transcendent—they would benefit from exposure to diverse understandings of illness, understandings of God/the transcendent, spiritual coping resources, and spiritual practices. In addition, people who engage in practices where they both give and receive care generally experience “greater life satisfaction and more positive attitudes” compared to people who do not engage in support activities at all or who only function as caregiver or care-receiver (Pargament, 1997, p. 212).

Women in group direction would also be able to share success stories of adapting to life with chronic illnesses, serving as examples of hope for one another. The opportunity to learn from each other and the support of the community would help women in their efforts to understand and change their own life-limiting embedded beliefs, work that is challenging to initiate and sustain (Pargament, 2007, p. 171). Finally, women interested in engaging in illness advocacy work or resisting life-limiting social expectations of women and relational power dynamics with medical experts could

support each other in these efforts (Bell, 1987, pp. 97-98; Neuger, 2001, p. 134; Sered, 1992, p. 8).

### **Narrative, contextual, and collaborative dimensions.**

In the following sections of this chapter, I provide insight into three particularly relevant dimensions of spiritual direction—the narrative, contextual, and collaborative dimensions—that create a safe and sacred container for women with autoimmune diseases to experience healing, make meaning, and strengthen their relationships with God/the transcendent. The narrative dimension supports lament and meaning making, the contextual dimension supports intercultural care, and the collaborative dimension supports a feminist-oriented model of spiritual direction in which women can safely lament, make meaning, and resist oppressive power discourses that contribute to disenfranchised losses associated with RA, MS, and lupus.

### ***Narrative dimension of spiritual direction.***

In this dissertation, narrative refers to the way people order their lives and construct meaning through stories. Narrative approaches to care assume that although people seek ways to reinforce the plots of their stories, they are also able to reconstruct more life-enhancing narratives when existing stories do not contribute to their well-being in life-enhancing ways (e.g., Neuger, 2001; White & Epston, 1990). Illness narratives work similarly: people rely on their embedded understandings of illness, particularly

during the crisis phase of diagnosis, but over time they may be able to integrate new information into their meaning making framework.

Generally speaking, pastoral/spiritual care is a narrative approach to care that has been described as the study of “living human documents” (e.g., Gerkin, 1984). Spiritual direction is a particular form of narrative-driven spiritual care. Within the context of the spiritual direction relationship, stories—and “spiritual direction is *always* storytelling” (Guenther, 1992, p. 32, emphasis in original)—can be told, reinforced, and/or reconstructed safely and confidentially. Director and directee encounter God/the transcendent and engage in constructive theological meaning making within the narratives they explore together (Bidwell, 2004a).

As Mary shares her story each month in spiritual direction, she and Jane discern the ways in which God/the transcendent may have been at work in Mary’s life. For example, God/the transcendent may have worked through Mary’s feelings, such as the time Mary “knew instinctively and immediately” that spiritual direction could help her cope more effectively with lupus. God/the transcendent may have worked through other people (e.g., Mary’s psychiatrist may have suggested that Mary seek help with her anger at God from a pastoral or spiritual caregiver), or God/the transcendent may have worked through patterns or “coincidences” that Mary and her director notice when Mary shares her story. For example, Mary shared with Jane that she had come across the phrase “seek and you shall find” in her daily devotional reading and in an e-mail from a friend who lives in another city. Mary also noticed that when she explored the Spiritual Directors International website, she found that their on-line tool for locating a spiritual director is

called the *Seek and Find Guide*. Mary wondered if there was a message in the repeated appearance of the “seek and find” phrase. The women engaged in meaning making around Mary’s question. Together they affirmed that these messages aligned with Mary’s life-enhancing images of a loving God who communicates with her and guides her. They discerned that the repeated “seek and find” messages had encouraged Mary to continue looking for the help she needed to address her spiritual struggles. They also discerned that Mary had appropriately responded to this movement of God in her life, and Mary would continue to reflect on ways she might continue to seek and find God at work in her life.

Women with autoimmune diseases may find that simply telling their stories has a healing effect, especially when they share their narratives with spiritual directors who listen attentively, are present to suffering and lament, and acknowledge experiences of loss. Although it can be difficult for people to relive troubling experiences, research on the effects of disclosure of traumatic events shows that negative emotions evoked immediately after sharing are short-lived, yielding to long-term therapeutic benefits, such as enhanced well-being (e.g., J. E. Kelley, Lumley, & Leisen, 1997; Kleinman, 1988; Pennebaker, 1997). The people who derive the greatest healing benefits from sharing their stories are those people who implicitly or explicitly make meaning of their narratives. As described in Chapter Three, meaning making is an essential aspect of healing after a loss and is central to the work of healing/sustaining<sup>13</sup> a person in the

---

<sup>13</sup> Recall from Chapter One Hiltner’s definition of *sustaining*: “the ministry of support and encouragement through standing by when what had been a whole has been broken or impaired and is incapable of total situational restoration, or at least not now” (p. 116) and my definition of *healing* as relief from suffering.

experience of chronic illness. The power inherent in narrative approaches to psychospiritual care underscores the potential for spiritual direction to be particularly helpful for women with autoimmune diseases who need to grieve ongoing losses and make meaning of their illness experiences.

Within the spiritual direction relationship, director and directee seek to recognize and interpret the presence and activity of God/the transcendent within the directee's spiritual narrative. They also seek to understand the meaning of the directee's story within the context of the directee's spiritual orienting system, and they determine appropriate responses to these new understandings, metaphorically writing a tentative, yet hope-filled script for the next chapter in the directee's story. Complex theological meaning making is an integral part of spiritual direction as directee and director continually co-construct new theological narratives through prayerful and contemplative discernment, seeking to establish, restore, and/or maintain a well-integrated spirituality for the directee.

Before she discovered spiritual direction, Mary was confused by and desperate to understand how a just God (her embedded image of God) could punish her—a woman who had, in good faith, created an idyllic life of career, husband, children, dog, faith community, and material wealth—with two incurable diseases. Mary had often said of other people when they experienced illness or injury that “God comforts the afflicted and afflicts the comfortable,” an aphorism that encapsulated her understanding of a just God. Through theological meaning making discussions with her spiritual director, Mary wrestled with the ways in which her embedded understandings of God conflicted with the image of a loving God who suffered with

---

through the restoration of relational harmony with self (i.e., reintegration of body, mind, and spirit), others, the environment, and/or God/the transcendent.

her, an image she now needed in times of illness-in-the-foreground. In times of wellness-in-the-foreground, Mary found comfort and purpose in a pedagogical understanding of suffering in which her financial, relational, and professional successes provided support for her to undertake the spiritual challenges inherent in her illness experiences. Through this complex theological meaning making, Mary was able to transform life-limiting feelings of personal blame for her illnesses to life-enhancing understandings of illness as an opportunity to grow stronger in her relationship with God. Mary's hope-filled script for the next chapter of her life includes plans to lament the losses she has experienced with a diabetic co-worker who has offered to talk about chronic illness, and she is writing weekly reflections in a journal about the ways in which her illness has "comforted the afflicted and afflicted the comfortable" aspects of her own life.

### *Contextual dimension of spiritual direction.*

Spiritual direction is also a contextual relationship in which new, provisional, and individualized understandings of the directee's life and relationship with God/the transcendent are constructed during the spiritual guidance encounter. This approach to care echoes the tenets of the pastoral theological model of intercultural spiritual care articulated by Doehring (2010). Using an intercultural approach to care, caregivers attend to differences between their spiritual beliefs and directees' beliefs so that the director does not inadvertently impose his or her beliefs on the directee in the meaning making process (which would be using a universalist approach to care).<sup>14</sup> The spiritual director's

---

<sup>14</sup> Intercultural spiritual care also resonates with constructivist psychotherapeutic understandings of grief and loss that privilege the client's language, story, and meaning making over the therapist's ideas and expressions, resulting in "a more responsive frame for holding the complexity of loss as a lived experience" (Neimeyer, 2001b, p. 289).



deep respect for the authority of the directee's experiences is described within spiritual direction literature as the practice of *not-knowing*.<sup>15</sup>

The high regard with which a spiritual director holds the directee's experiences is illustrated in the informal canon of historical writings on spiritual direction, such as the fourth-century accounts of Abba Antony (Athanasius, trans. 1980) and the sixteenth-century chronicles of Teresa of Ávila (trans. 1961). The importance of privileging directee experience and narrative is more explicitly stated in contemporary writings (e.g., Bidwell, 2004b, p. 14; T. Edwards, 2001, pp. 8-9; Fischer, 1988, p. 20; Guenther, 1992, p. 43). Given the propensity today for health care providers to assert themselves as experts on a woman's body and her illness experiences, it is particularly important for women with autoimmune diseases to claim the authority of their experiences (as I articulated in Chapter Two's description of a woman's potential loss of self-agency related to chronic illness).

Mary's spiritual director Jane recognizes that Mary's descriptions of pain, fatigue, depression, and loss associated with lupus and Parkinson's disease matter in the context of their spiritual direction conversations. Jane is aware of her own knowledge about these diseases and their treatments, her expectations of people with chronic health conditions, and her personal experiences of illness and experiences with other people who have these diseases. During spiritual direction sessions with Mary, Jane intentionally and continually notices and sets aside her assumptions to keep Mary's experiences and understandings at the center of their attention.

---

<sup>15</sup> Contemporary psychological literature describing constructivist approaches to care (e.g., Neimeyer & Keesee, 1998, p. 228) and narrative theory (e.g., Neuger, 2001, p. 45) also use the term *not-knowing* in this way.

Although individual spiritual directors will hold theological understandings of illness that are as diverse as directees' views on the topic, an intercultural approach to care helps ensure that the directee's constructive theological process is primary. For example, Mary's spiritual director may or may not believe that Mary "deserves" to have lupus and Parkinson's disease (as Mary lamented when the women first met), but if Jane is using an intercultural approach to care, she will be aware of her own beliefs and take care to not impose them on Mary. Jane will also remain aware that differences in their beliefs heighten the potential for Jane to disengage from Mary in the meaning making process when they do not agree (e.g., Jane might shift the conversation to another topic, or she might not engage Mary in active collaborative meaning making on a particular topic). Jane will work with Mary, in the context of *Mary's* spiritual orienting system, to construct life-enhancing understandings of the illness experience for Mary at that time.

The contextual nature of spiritual direction also ensures that director and directee attend to the effectiveness of the directee's spiritual coping strategies and spiritual practices. What is a life-enhancing coping strategy or spiritual practice for one person may be life-limiting for another person, even one living with the same disease. For example, Mary's plan to journal about her illness might prove stressful for another woman because the other woman feels her reflections should be kept private so that they cannot be judged by others who might read her journal. Together director and directee can evaluate spiritual practices to ensure that they support the directee's life-enhancing meaning making and help her move toward health and well-being.

*Collaborative dimension of spiritual direction.*

Spiritual direction is a practice grounded in the collaborative efforts of director and directee working with God/the transcendent to enhance the directee's well-being and strengthen the relationship between the directee and God/the transcendent. Spiritual direction is practiced with the express understanding that God/the transcendent is participating in this spiritual work. Collaborative spiritual coping practices in which people interact with God/the transcendent to cope with struggles result in "higher levels of competence" in times of stress than deferring approaches (when people give all control to God/the transcendent) or self-directing approaches (when the person relies on herself to resolve problems) (Pargament, 1997, pp. 293-294). Although there are no empirical studies to confirm this assertion, one could assume that the collaborative process of spiritual direction would reinforce the type of collaborative coping described in the religious/spiritual coping literature.

The nonhierarchical, collaborative dimension of spiritual direction exemplifies feminist understandings of caregiving relationships that assert a woman's authority to claim her unique experiences and ways of knowing as valid and valuable (including her experiences and ways of knowing God/the transcendent) (Neuger, 2001, p. 2). In this caregiving context, women can feel safe enough to share and lament their illness experiences, especially experiences of loss. Particularly in a group model of spiritual direction, women who share experiences of living with autoimmune conditions can support each other and work together as they resist oppressive power discourses (e.g., the dominant patriarchal structure of the biomedical establishment) that contribute to

disenfranchised losses associated with RA, MS, and lupus. As I will articulate more fully in Chapter Five, director and directee(s) can also collaborate to develop healing rituals that acknowledge losses, a practice that is powerful when performed and experienced in community (Hogue, 2003, p. 141).

Participation in spiritual direction also provides women with the opportunity to invest in themselves. Self-care is often neglected by women who are in good health. It is even more challenging for women with chronic illnesses to attend to their psychospiritual needs when they feel guilty about constant attention to physical care or when psychospiritual needs are disenfranchised. As a social worker, wife, and mother, Mary may find it difficult to disengage from her many caregiving roles. The practice of spiritual direction guarantees that Mary will have some time in her life completely dedicated to her and her deepest spiritual needs. This would be true in both one-on-one and group settings. Even though she would also give to others in a group, when it was Mary's turn to be the directee, she would be the center of contemplative attention.

## **Summary**

There is no one "best" caregiving approach for all women with autoimmune diseases. My evaluation of biomedical, psychological, and pastoral approaches to care indicates that spiritual direction has the greatest potential to meet the unique psychospiritual needs of women with autoimmune diseases. Contemporary spiritual direction, grounded in the Christian tradition, provides the framework for a long-term, intercultural, and psychospiritual approach to care for women who have autoimmune

diseases, both in times of wellness-in-the-foreground and in times of illness-in-the-foreground. In this context of attending to a woman's relationship with God/the transcendent, the narrative, contextual, and collaborative dimensions of spiritual direction support complex, contextual theological meaning making, attending to effective spiritual coping strategies and spiritual practices, and creating a safe place for lament and public acknowledgment of losses. Having established the theoretical grounds for spiritual direction as an appropriate context for care for women with RA, MS, and lupus, I turn to the practicalities of what a model of spiritual direction for this population might look like.

## **Chapter Five: A Model of Spiritual Direction for Women with Autoimmune Diseases**

This dissertation addresses the psychospiritual needs of the growing number of women in the U.S. who have autoimmune diseases, particularly rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus. I began with a survey of medical and psychological literature to develop a portrayal of how women experience these disorders. This depiction includes medically-oriented descriptions of the diseases, as well as the shared illness experiences of delayed diagnosis; chronic pain, fatigue, and depression; and liminality (existing along continua of healthy/sick and healing/suffering). Women with RA, MS, and lupus also experience ongoing losses, some of which may be disenfranchised. I described four categories of such losses that occur with autoimmune diseases: losses of identity, relationships, self-agency, and spiritual beliefs and practices. Losses and other life-diminishing illness experiences continue and may even increase over the years of living with these degenerative disorders. Ongoing experiences of suffering and loss disrupt a woman's spiritual equilibrium and become catalysts for meaning making. When a woman experiences disenfranchised losses and/or cannot make sense of her illness experiences, she may be unable to sustain a well-integrated spirituality, and she is at risk of getting stuck in chronic spiritual struggles that can negatively affect her health and well-being.

Because meaning making about illness experiences shapes and is shaped by a person's spirituality and relationship with God/the transcendent, I expanded the rich description of autoimmune disease with further exploration of meaning making related to chronic health conditions. Using disability theologies (Creamer, 2009; Eiesland, 1994) and Nelson's (2003) paradigms of suffering, I examined the underlying theological implications of the three most common models of understanding illness and disability: the moral model, the biomedical model, and the social model. This theological reflection eventuated in provisional constructive theological claims about a woman's psychospiritual experiences of autoimmune disease and her unique needs for care. I asserted that women with autoimmune diseases need to lament and have losses acknowledged, and they need to engage in ongoing (over the course of years), complex, and contextual theological meaning making. Their meaning making needs to consider ongoing shifts between wellness-in-the-foreground and illness-in-the-foreground perspectives in order to help women cope effectively with the ambiguous nature of chronic illness. In addition, women with RA, MS, and lupus need to enact their theological meaning making through life-enhancing coping strategies and spiritual practices.

Using these theological claims, I evaluated medical, psychological, and pastoral approaches to care. I concluded that spiritual direction (in a one-on-one relationship or in a group setting) would be the best context in which to address the long-term psychospiritual needs of women with autoimmune disorders. Spiritual direction explicitly focuses on a person's relationship with God/the transcendent, and it can support the type

of long-term relationships needed by women living with incurable diseases. In addition, the narrative, contextual, and collaborative dimensions of spiritual direction support the necessary elements of a specific model of spiritual direction for women with autoimmune diseases. This model includes: (1) spiritual directors informed by women's experiences of autoimmune disease and prepared to balance a woman's need to engage in transformative spiritual struggles with the risks posed by getting stuck in chronic spiritual struggles, (2) an intercultural and feminist approach to spiritual direction that privileges women's experiences and understandings of illness and God/the transcendent, (3) complex and contextual theological meaning making through narrative and ritual practices that takes into account potential disenfranchised losses and the shifting perspectives of illness-in-the-foreground and wellness-in-the-foreground, (4) attention to the ways women enact life-enhancing theological understandings of illness and God/the transcendent in their coping strategies and spiritual practices, and (5) co-construction and performance of rituals that acknowledge losses and facilitate transitions between illness-in-the-foreground and wellness-in-the-foreground perspectives.

### **An Explicitly Intercultural Approach to Care**

As noted in Chapter Four, the collaborative nature of spiritual direction is ideally suited for an explicitly intercultural approach to care that privileges directees' understandings of spirituality, religion, and God/the transcendent. I believe the intercultural approach is already implicitly embedded in contemporary spiritual direction through not-knowing, the practice of privileging the spirituality and experiences of the



directee over the director's beliefs and experiences. In this model of spiritual direction for women with autoimmune diseases, intercultural care also extends to experiences and beliefs related to illness and disability. Spiritual directors using an intercultural approach with women who have RA, MS, and lupus need to honor the complex and idiosyncratic nature of both spirituality and illness experiences.

Intercultural care is particularly important when working with a directee as she makes meaning of her illness experiences. Spiritual directors need to be aware of the ways in which people understand illness experiences (as described in Chapter Three) so that directors do not impose personal biases on directees. I briefly described the practice of intercultural spiritual care in Chapter Four; now I will provide a more detailed illustration of intercultural spiritual care with Mary and her spiritual director Jane.

After her introductory meeting with Mary, Jane reflects on her perceptions of the women's similarities and differences. The women are alike in many aspects of social identity: they are both middle-class, college-educated, heterosexual, Caucasian women in their forties who live relatively stable lifestyles in suburban homes with traditional families that include a spouse and children. The women differ in their religious upbringings and in their experiences of health and illness.

Mary and her husband are now part of a Quaker community, but Mary grew up in an evangelical religious tradition in which faithful followers sought and received divine healing. Mary's embedded understanding of her relationship with God might be described as transactional: she believes her acceptance of Christ as Savior at the age of nine saved her from eternal damnation, but she remains obligated to live as free from sin

as possible in order to maintain her relationship with God and all the good in life that God provides, including divine healing. She believes that a just God cares for faithful followers with a good life, including good health. Mary also believes a just God prompts people to return to “right relationship” by challenging them with difficult experiences (including illness) that cause people to seek God for comfort and guidance.

Jane is a practicing Episcopalian and has been actively involved for over twenty years in a church community that encourages critical thinking about God and faith. Jane understands God/the transcendent to be a loving spirit present in all life experiences, including illness, more often working through people to heal than offering miraculous cures. Although her identity is Christian, Jane reads widely about all religious and spiritual traditions, and she is committed to a number of spiritual practices, some of them from non-Christian traditions. In addition to their religious differences, Jane also recognizes that her own stable physical and mental health and a family history with few incidences of chronic illnesses might affect her ability to be an effective spiritual director for Mary.

At their first meeting, Mary explained that her spiritual struggles with her illnesses had prompted her to explore spiritual direction, and Jane realized that illness could play an important role in Mary’s ongoing spiritual journey. Jane gained insight into Mary’s understandings of God/the transcendent and illness through Mary’s questions and assertions about God’s role in her diagnoses of lupus and Parkinson’s disease (Where was God? What had I done to deserve this? God has betrayed me!!). Jane does not believe that Mary “deserves” lupus or Parkinson’s disease, and she does not believe that

God would “betray” a faithful person with disease in order to draw them into closer relationship. Jane believes that disease is a normal experience of the human body in a created world where joy and suffering co-exist. She also believes that all circumstances of life, including suffering, provide opportunities for people to develop stronger relationships with God/the transcendent. Jane recognizes that these beliefs might prompt her to judge Mary’s struggles with a God who “betrays” people with illness. Jane also recognizes that she has the propensity to disengage from Mary’s struggles about God and illness if she cannot set aside her own convictions during their times together.

When they meet for spiritual direction, Jane is careful to not assume that Mary will eventually “come around” to Jane’s ways of thinking about God/the transcendent, sin, suffering, or illness. However, Jane is also aware that Mary’s beliefs could be problematic if Mary continues to search for what she has done to deserve her illnesses and if these beliefs continue to disrupt her relationship with God. Jane challenges herself to intentionally welcome Mary’s laments of God’s betrayal. During their time together, Jane also consciously monitors her tendency to judge Mary’s feelings. Even though Jane does not share Mary’s understandings of illness, as Jane acknowledges Mary’s suffering and holds Mary’s experiences and understandings in the highest regard, the women form a relationship of trust that can facilitate healing.

During their first few sessions of spiritual direction, Jane is aware that Mary has an illness-in-the-foreground perspective because Mary begins their conversations by talking about the intensity of her pain that day. Jane focuses on being a comforting, gently probing presence as Mary laments her physical and spiritual pain. When Mary

appears for their next spiritual direction session feeling good physically and exhibiting a wellness-in-the-foreground perspective, Jane and Mary begin to deliberately examine Mary's spiritual well-being and her relationship with God through her narratives, coping strategies, and spiritual practices, looking for ways to sustain what is life-enhancing for Mary and transform what is life-diminishing.

As the case study with Mary and Jane illustrates, a spiritual director needs to be aware of her own beliefs and biases in order to prevent them from intruding into the directee's spiritual world. Explicitly engaging the practice of intercultural spiritual care helps spiritual directors focus on the relationship at the center of spiritual direction, the relationship between the directee and God/the transcendent. Within this context of spiritual care that privileges the directee's experiences and beliefs, director and directee can reflect on specific narratives, coping strategies, and spiritual practices that help alleviate and prevent women from getting stuck in chronic spiritual struggles.

### **Narratives, Coping Strategies, and Spiritual Practices**

The provisional theological claims constructed in Chapter Three assert that women with RA, MS, and lupus would benefit from theological understandings of illness that embrace the ambiguous nature of a created world in which limits such as illness and disability are expected, normal dimensions of the human condition. I claimed that women with chronic conditions would also benefit from spiritual care tailored to the liminal nature of chronic illness. When illness is in the foreground, women need to share their experiences of loss, have losses acknowledged, and construct or rely on narratives in

which God/the transcendent is with them in their suffering. When wellness is in the foreground, women may be more responsive to understandings of God/the transcendent and practices that facilitate the construction of hope-filled narratives and support benefit-finding related to their illness experiences. Women communicate, enact, or “perform” their theological beliefs and values, and they embody their spiritual orienting system through narratives, coping strategies, and spiritual practices (Doehring, 2010, p. 6; see also Becker, 1999, p. 153 and E. L. Graham, 1996).

### **Narratives.**

Helping people share their stories has been portrayed as “the most significant pastoral task” (E. Graham et al., 2005, p. 67). As I noted in Chapter Four, simply sharing stories can be healing, and during times when illness is in the foreground, telling her story may be all that a woman can or wants to do. During these times, some people may even find attempts to reconstruct meaning to be “highly offensive, perhaps even blasphemous” (Calhoun & Tedeschi, 2001, p. 167). Spiritual directors need to balance a woman’s need for lament and struggle with the potential negative health effects of struggles that become chronic concerns. Attending to the frequency and duration of particular struggles and the relative well-being of the directee over the course of months will help spiritual directors discern when spiritual struggles may become problematic for particular directees.

When working with women who have autoimmune diseases, spiritual directors should also attend to the balance between acknowledging and addressing limiting aspects

of the directee's chronic health condition and creating and sustaining a hope-filled narrative that reinforces her connection with God/the transcendent (Hogue, 2003, p. 91; Loffer, 2000, pp. 302-400; Underwood, 2006, p. 7). It is important to recognize that hope-filled narratives do not always include finding benefits in the illness experience (Davis, 2001, p. 146); the hope put forth in these narratives may simply assert the possibility that a woman can live with her illness without struggling against it.

As described in Chapter Three, women often use metaphors in their illness narratives. Metaphors can be helpful vehicles for narrative reconstruction because "metaphor lies at the intersection of what has been and what can be" (Becker, 1999, p. 65). Returning to the case study, I will illustrate how Jane might help Mary construct a new hope-filled narrative using Mary's metaphor of "chaos" to describe lupus.

In her laments about lupus, Mary repeatedly uses "chaos" to describe the way the disease destroys the order in her life. She tells Jane she feels "out of control," as though she is "spinning helplessly." After exploring the negative psychological and spiritual consequences of these feelings, the women agree that this chaos narrative is not life-enhancing for Mary, even though it vividly captures many aspects of her illness experiences. Jane asks Mary if it would help her to hear about an alternative definition of chaos based on scientific notions of chaos theory. Mary is eager to explore a new way of understanding her feelings of chaos, and she asks Jane to tell her more. Jane explains that chaos theory has two key principles: small changes can affect bigger complex systems in unpredictable ways, and a deeper order undergirds the chaotic disorder.

Mary is open to exploring whether a new “chaos theory” narrative might be helpful for her, and the two women reflect on Mary’s experiences in light of chaos theory’s two key principles. Although being diagnosed with two incurable diseases was not a “small” change for Mary, when she considers her life as a complex system that extends to family, friends, professional networks, church, neighborhood, and community, and when she thinks of herself as a complex being made up of physical, emotional, intellectual, and spiritual dimensions, Mary acknowledges that lupus is relatively “smaller” than the whole that is her world.

Mary also finds some comfort in chaos theory’s notion that change occurs throughout a system in unpredictable ways. This idea resonates with Mary’s experiences of the unpredictable nature of chronic illness flares and remissions. Mary and Jane then reflect on the ways Mary’s life still maintains a deeper supporting structure, even though this structure is sometimes obscured by challenges associated with chronic illness. They explicitly search for the foundational beliefs and practices expressed in Mary’s spirituality. With Jane’s help, Mary identifies her relationship with God, contemplative prayer practices, and meaningful relationships with her family and clients as part of the deeper structure of Mary’s life. Even though these structural supports have been affected by the chaos of illness, the women agree that they are still fundamentally sound.

In this meaning making exercise, the women have implicitly engaged Nelson’s (2003) eschatological imagination paradigm of suffering, refocusing Mary’s attention on the presence of God/the transcendent in the good moments of everyday life (a practice that resonates with Mary’s Quakerism) and helping Mary renew her faith in the promise

that she will ultimately (i.e., in the afterlife) be relieved of suffering, a belief that she also identifies as a part of the deep structure of her life. The women agree that the new chaos theory metaphor is ambiguous enough to express the limits and complexity that Mary experiences with chronic illness even as it helps Mary find hope and stability in her deep and grounding relationship with God.

At the end of their session, Mary no longer feels like she is “spinning helplessly.” Rather, she is encouraged by God’s presence with her in the form of Jane’s spiritual companionship and in the goodness she knows exists in everyday life, and she is eager to experiment in the coming month with spiritual practices that draw upon this new perspective on her illness experience. Her new chaos theory narrative and related spiritual practices may need further reconstruction the next time the women meet, but Mary leaves the spiritual direction session feeling hopeful that she will be able to live with her illnesses more effectively in the days ahead.

If Mary and Jane’s work together in spiritual direction stops at an intellectual level with narrative reconstruction, Mary may not experience the full benefits of new life-enhancing theological understandings. Her coping strategies and spiritual practices also need to be transformed so that she does not unconsciously reinforce life-limiting theologies embedded in existing strategies and practices. As an informed spiritual director, Jane can help ensure that this integrative work takes place by helping Mary sustain and find spiritual practices that incorporate her new life-enhancing theological understandings. The following section further explores these dimensions of spiritual direction with women who have autoimmune diseases.



### **Coping strategies and spiritual practices.**

People use a variety of coping behaviors to alleviate suffering (e.g., self-medicating, exercising, journaling, sleeping, praying, complaining). Coping may or may not explicitly engage a person's spirituality, but coping strategies frequently do involve spiritual practices, particularly prayer. People often use spiritual coping strategies when they have exhausted the limits of what they can do on their own, when they need to connect with resources beyond themselves, such as God/ the transcendent (Pargament, 1997, p. 310). Not all spiritual coping is life-enhancing, as the research of Pargament, Koenig, and others has empirically demonstrated (e.g., Pargament, Ano, & Wachholtz, 2005, pp. 484-485; Pargament, Koenig, & Perez, 2000). If spiritual coping draws upon the kinds of life-limiting theologies of illness and disability described in Chapter Three, it can also become life-limiting. Life-limiting coping exacerbates pain, loss, and suffering. Recall that it is not necessary to eliminate all pain, loss, or suffering, as these experiences are part of life and may result in positive spiritual growth or transformation (Pargament, 1997, p. 314). Some women may also cope in ways that enhance well-being in spite of experiences of pain, loss, and suffering.<sup>1</sup> Rather, spiritual directors should monitor directee struggles and coping strategies for congruence with life-enhancing theological understandings, and they should be attentive to the potential for directees to become stuck in chronic struggles.

In some cases, *coping strategies* and *spiritual practices* are overlapping terms.

For example, prayer fits both categories. Prayer as a means of communicating with or

---

<sup>1</sup> In my personal experience, low-to-moderate levels of pain and fatigue do not generally interfere with my overall sense of well-being. However, there does appear to be some threshold at which these experiences become suffering that gets in the way of well-being.

seeking the presence of God/the transcendent may be a coping strategy, or a type of behavior people use to help them manage stress. People may engage in such behaviors during non-stressful times as well.<sup>2</sup> Prayer is also a spiritual practice, although when talked about in this way, it is often more defined as to type or style (e.g., praying the rosary, walking prayer, communal prayer). A person might rely on a different prayer practice in times of stress (e.g., petitionary prayer) compared to the type of prayer she uses during times of non-stress (e.g., contemplative prayer).

The model of spiritual direction I propose in this dissertation is an explicitly spiritual coping strategy (seeking spiritual support and/or guidance)<sup>3</sup> to help women with autoimmune diseases live with the stress of unpredictable and incurable health conditions. As a spiritual coping strategy, spiritual direction augments other coping strategies likely to be employed by women with RA, MS, and lupus, such as seeking medical care, exercising, and negotiating healthy boundaries. I have also described spiritual direction as a spiritual practice focused on reinforcing a woman's relationship with God/the transcendent, a practice women participate in during both times of stress and times of non-stress. In this chapter, I also describe other coping strategies (e.g., narrative reconstruction and ritual) that can be explicitly spiritual in nature, and, when

---

<sup>2</sup> People may also engage in behaviors used in coping to sustain well-being, prevent potential stress, or simply because they are enjoyable behaviors. For example, a woman may overeat in response to a stressful argument with her partner, overeat to prevent low blood sugar when she knows she will miss a meal later, or overeat during holiday meals as a celebratory act.

<sup>3</sup> The Brief RCOPE measurement tool identifies the following religious coping strategies (Pargament et al., 2000): benevolent religious reappraisal, punishing God reappraisal, demonic reappraisal, reappraisal of God's powers, collaborative religious coping, active religious surrender, passive religious deferral, pleading for direct intercession, self-directing religious coping, seeking spiritual support, religious focus, religious purification, spiritual connection, spiritual discontent, marking religious boundaries, seeking support from clergy or members, religious helping, interpersonal religious discontent, seeking religious direction, religious conversion, and religious forgiving.

used in a cohesive and intentional way within the context of spiritual direction, constitute a model of spiritual care that meets the unique needs of women who have autoimmune diseases.

There is a growing body of literature on religious/spiritual coping, which I will not attempt to summarize here.<sup>4</sup> Rather, I will focus on one aspect of coping: the three generally accepted coping *styles*. This information will help spiritual directors assess when a directee's coping strategies reinforce or work in opposition to life-enhancing theological understandings of illness. The relative effectiveness of a coping strategy or spiritual practice varies by person and circumstance, and I defer to individual spiritual directors and directees to discern which strategies and practices are most appropriate for a directee at any particular time.

People generally approach coping in relationship to God/the transcendent in the following ways:

(1) the self-directing approach, wherein people rely on themselves in coping rather than on God[the transcendent], (2) the deferring approach, in which the responsibility for coping is passively deferred to God[the transcendent]; and (3) the collaborative approach, in which the individual and God[the transcendent] are both active partners in coping. (Pargament, 1997, p. 180)

Of these three styles of coping, a collaborative approach is associated with better health and well-being.

The self-directing and deferring styles have had mixed outcomes, leading researchers to differentiate subtypes of coping within each of these styles. Within the

---

<sup>4</sup> Readers interested in an in-depth exploration of religious/spiritual coping should consult the work of Kenneth Pargament and colleagues (e.g., Bush et al., 1999; Cole & Pargament, 1999b; Pargament, 1997; Pargament, Ano, et al., 2005; Pargament, Smith, Koenig, & Perez, 1998).

self-directing style, two subtypes have been tested. A “deistic and supportive but not intervening God” subscale correlated with both positive (higher beliefs in personal control, life satisfaction, and spiritual and personal well-being) and negative (higher anxiety, hostility and depression) mental health outcomes. An “abandoning God” subscale correlated with negative mental health outcomes (lower levels of self-esteem and less active problem solving and higher anxiety) (Phillips, Pargament, Lynn, & Crossley, 2004).

The deferring style tends to correlate with positive outcomes when people feel they have no control over what is happening, like the situation of being trapped in a physical location during a natural disaster. When people can take action, this style correlates with higher depression and lower self-confidence. Researchers have explored whether deferring needs to be distinguished from surrender, which

may relate to collaborative coping in that both the individual and God are active in solving the problems. However, it goes beyond collaborative coping in that when one’s solution differs from God’s, the surrendering believer chooses to follow God’s ways . . . ‘Not as I will, but as You will . . .’ (Matt. 26:39). (Wong-McDonald & Gorsuch, 2000, p. 149)

In an initial study, the surrender style correlated positively with religious importance and spiritual well-being.

Because coping research findings are not definitive, they should be considered guidelines for contextual approaches to care that consider the particularities and holistic well-being of each woman. The case study will illustrate how a spiritual director might assess coping strategies and spiritual practices with a woman who has an autoimmune condition.

When Mary and Jane met, Mary described two primary spiritual practices that reflected her connection to the Quaker tradition: seeking God in all things and contemplative prayer. Mary actively sought God's presence and communication in all experiences of her life, and she therefore expected God to communicate to her through her illness experiences. Mary also relied on her understanding that God rewarded faithful behavior with a good life. When she was diagnosed with lupus and Parkinson's disease, Mary did not believe she had done anything to deserve these illnesses, and she felt betrayed by God. As a result of this sense of betrayal, Mary became distraught and depressed.

In the two years that had elapsed between her diagnosis and her first meeting with Jane, Mary had not passively waited on God to respond to her physical, psychological, and spiritual struggles. Mary sought help from medical and psychological caregivers, and she remained actively engaged in personal and corporate prayer and discernment to cope with and understand her illness experiences. But, because the onset of these illnesses did not mesh with her embedded understandings of a just God, Mary believed God had betrayed her. As she struggled to restore equilibrium to her disrupted spiritual orienting system and relationship with God, Mary got stuck in her spiritual questions of Why me? and What have I done to deserve this? Eventually, she invited Jane to companion her in spiritual direction in order to explore another way to restore her relationship with and engage God in her meaning making and coping. From this description of Mary's process of coping with her illnesses, Jane discerned that Mary predominantly used a collaborative style in which she sought to partner with God in times of struggle.

After reconstructing Mary's illness narrative using the metaphor of chaos theory, the women assessed Mary's coping and spiritual practices. They discerned that actively collaborating with God to make meaning of her experiences (through regular participation in spiritual direction, a spiritual formation group, and Quaker prayer services), listening to soothing music, reflective journaling, and lamenting losses all supported Mary's new life-enhancing narrative. Jane was aware that people are more inclined to collaborate with a loving God (compared to a punitive God) (Gall & Grant, 2005, p. 523), and she believed that helping strengthen Mary's images of a just and loving God would also reinforce Mary's predominantly collaborative approach to coping. However, Mary's definition of "just" may require reconstruction to fully interweave life-enhancing understandings of God into her new chaos theory narrative.

In future sessions together, Jane will also offer Mary opportunities to co-construct and perform ritual practices as another collaborative coping strategy that addresses two particular struggles associated with autoimmune diseases: the shifting perspectives of chronic illness and disenfranchised losses. In the following sections, I explore the use of ritual with women who have RA, MS, and lupus.

### **Using Ritual with Women Who Have Autoimmune Diseases**

The contextual and collaborative dimensions of spiritual direction make it an optimal context in which women with RA, MS, and lupus can co-construct and participate in ritual practices that help address the complexities of their conditions (e.g.,

Reeves, 2007). In this dissertation, I am using a contemporary feminist description of *ritual* as

a strategic practice that women choose to negotiate the changes and transitions in their lives. It makes creative use of symbol and space to interpret and construct not only experience, but theo/alogy and spirituality. It is contextual and strategic—its aim not only to express existing reality, but to change and make a difference to their context. (Berry, 2009, p. 129)

This definition supports traditional understandings of ritual as practices that facilitate shifts from ordinary time and space to sacred time and space in order to affect personal and communal transformation in relationship with God/the transcendent (Kinsley, 1996, p. 121; Smith, 1980, pp. 124-125). It also supports traditional understandings of ritual as practices that help realize the ideals, hopes, values, and beliefs of a group through the embodied integration of thought and action (Bell, 1987, pp. 97-98).

Like narrative, rituals also tell a story with a definitive beginning, middle, and end (Hogue, 2003, p. 144). Ritual activity within the context of spiritual direction provides another opportunity for constructive theological meaning making through *poesis*, storytelling that relies on metaphor, symbols and symbolic action. Nonverbal meaning making may be more accessible than narrative practices as a way for some women to acknowledge and respond to suffering (E. Graham et al., 2005, pp. 70-73), and nonverbal practices may also be an effective way for some women to connect difficult-to-articulate bodily experiences with narrative meaning making (Fischer, 1988, p. 165; Plach et al., 2004a, p. 151).

In this chapter, I present two types of ritual practices to support women with autoimmune diseases: (1) opening and closing rituals that attend to illness-in-the-

foreground and wellness-in-the-foreground perspectives and help establish the spiritual direction relationship as a safe space in which to explore illness without the disease dominating a woman's world when the spiritual direction session ends, and (2) rituals that acknowledge disenfranchised losses and empower women to resist the oppressive social discourses that may perpetuate such losses. I begin with guidelines for ritual construction and then describe and illustrate each type of ritual in more detail.

### **Guidelines for ritual construction and practice.**

Rituals can be as simple or as complex as the participants want them to be, but often the simplest rituals are the most effective (Hogue, 2003, p. 139; Mitchell & Anderson, 1983, p. 142). All participants should be involved in the ritual planning process. Planning should take into account who will participate or observe (rituals may be private to the participants or include other people, such as family members, as witnesses), when and where the ritual will take place, and how the space should be arranged (women frequently establish spaces that support non-hierarchical collaboration in community, such as circular configurations). Planning should also address how participants will carry out the ritual (e.g., sharing stories, lamenting, using symbols and symbolic acts, responding to each other, reading poetry or prose, singing or chanting, and performing various actions) and whether meaningful objects, readings, dress, or surroundings will help facilitate the ritual activity (Berry, 2009, pp. 17-24; Hammerschlag & Silverman, 1997, pp. 167-171; Reeves, 2007, p. 39).<sup>5</sup>

---

<sup>5</sup> Berry's (2009) book, *Ritual Making Women: Shaping Rites for Changing Lives*, provides a number of examples of rituals constructed by and for women.



During the ritual, the spiritual director should strive to maintain balance between the agreed-upon structure of the activity (e.g., by enforcing clear boundaries through starting and stopping points that provide a sense of safety around the liminal experience of the ritual) and the unfolding of the experience invoked in the participants, which introduces an element of risk for participants and observers (Hammerschlag & Silverman, 1997, pp. 129, 140; Hogue, 2003, pp. 164-165). The spiritual director should also ensure that there is time for reflection and integration during or after the ritual, either in silence or as part of a guided process (Hammerschlag & Silverman, 1997, p. 141; Hogue, 2003, p. 167; Kollar, 1989, p. 275).

In the following sections, I propose two types of rituals that may facilitate healing for women with RA, MS, and lupus. I begin with comments on the shifting perspectives of chronic illness, establishing the need for ritual work to attend to this dimension of the autoimmune disease experience. Then I propose the use of opening and closing rituals to facilitate the shifting perspectives of chronic illness in a spiritual direction session, and finally I describe the way ritual can be used in spiritual direction to acknowledge losses.

### **Illness-in-the-foreground and wellness-in-the-foreground perspectives.**

Recall that illness-in-the-foreground (IITF) is “characterized by a focus on the sickness, suffering, loss, and burden associated with living with a chronic illness; the chronic illness is viewed as destructive to self and others” (Paterson, 2001, p. 23). On the other hand, wellness-in-the-foreground (WITF) describes times when a woman experiences the fullness of herself and her life. In WITF, disease and illness represent one

dimension of life experience, and during this time a woman is able to reflect on and make meaning of illness experiences (Paterson, 2001, p. 23). These perspectives on chronic illness play an important role in helping a woman live well with autoimmune disease. An IITF perspective can prompt a woman to actively attend to her physical needs, such as protecting her body from further irreparable damage by taking appropriate medications or seeing her doctor for evaluation. In times of wellness-in-the-foreground, a woman can focus on and develop a strong, holistic self-identity that is not subsumed by illness, but does not deny her health condition either.

Illness-in-the-foreground and wellness-in-the-foreground can also be disadvantageous to a woman's long-term overall well-being. The potential exists for women in WITF experiences to engage in behavior that actually exacerbates health problems in the long run (e.g., a woman might overexert herself, skip medications, put off doctor visits, take on more responsibility than she will later be able to manage, or deny losses). Functioning within an IITF perspective can also threaten her well-being (e.g., by reinforcing identification with the sick role and attendant abdication of self-agency, making it difficult for her to engage in spiritual disciplines, or emphasizing the lack of control she feels she has over her body) (Mehl-Madrona, 2003, p. 219; Paterson, 2001, pp. 23-24). In order to "liv[e] with illness without living solely for it" (Charmaz, 1991, p. 661), a woman needs a strong self-identity that asserts itself during both IITF and WITF perspectives. Spiritual direction can help women negotiate these shifting perspectives to maintain realistic, holistic, and healthy ways of living with illness and to sustain her relationship with God/the transcendent during all of her illness experiences.

As I noted in Chapter Three, some women metaphorically describe and even personify illness as (for example) an enemy, intruder, bug, wolf, storm, invasion, bully, terrorist, or bomb. These images suggest that during times when illness is in the foreground, it not only dominates the woman's attention, but it also affects her identity. In other words, IITF perspectives may trigger shifts in her identity from woman, mother, wife, friend, and/or professional to warrior, protector, or exterminator—identities that reinforce the chosen metaphor and focus on illness and the body. In some health situations, imagery that suggests the person is defending the body from threat may help marshal energies in ways that promote healing or effective coping (e.g., when preparing for surgery or beginning chemotherapy, as described by Achterberg, Dossey, & Kolkmeier, 1994, pp. 37-55). Although taking on the enemy of disease in a particular battle may be helpful, engaging in an ongoing war<sup>6</sup> against an incurable disease—an enemy that cannot be vanquished—is not typically a life-enhancing strategy for the long term.

The need for a strong, consistent sense of self that does not acquiesce to illness and helps her “perceive life experiences as manageable, comprehensible and meaningful” (Faull & Hills, 2006, p. 735) suggests that spiritual direction should facilitate the transformation of illness metaphors from those that fight against the body or acquiesce to illness to metaphors that work with the body and strengthen a self-identity integrated in mind, body, and spirit. Helping women optimize their awareness of IITF and WITF perspectives through ritually-facilitated transitions in the spiritual direction encounter is one way to work toward the construction and conservation of a strong self-identity.

---

<sup>6</sup> Recall from Chapter Two that *battle* and *war* are common metaphors for illness.

I have often heard women with autoimmune diseases reject the idea of participating in disease-related support groups because they did not want to spend time focused on symptoms, disabilities, doctor visits, treatment regimens, and other disadvantages of living with an incurable condition. Some women may avoid this coping strategy because illness support groups implicitly threaten women's efforts to hold onto wellness perspectives that allow them to experience life in full (Paterson, 2001, p. 24). Other women may avoid groups in order to deny limits related to their illnesses. One-on-one spiritual direction relationships (rather than group direction) may be a way to engage women who have these kinds of concerns. Incorporating ritual into spiritual direction to intentionally manage shifts in wellness/illness perspectives may also help alleviate concerns that illness will dominate the spiritual direction session or a woman's life between sessions.

#### **Facilitating illness and wellness perspective shifts.**

Women's contemporary ritual-making activities tend to be more process-oriented than goal-oriented and reflect "ongoing struggle and journeying rather than decisive change" (Berry, 2009, p. 93). This feminist understanding of ritual is particularly useful in the context of spiritual direction with women who have RA, MS, and lupus because these conditions are characterized by ongoing struggles and a perpetual liminal experience that thwarts efforts to "achieve" a particular end state. So, although spiritual direction cannot help women transition out of the liminal reality of chronic illness, ritual

may be able to help women negotiate illness-in-the-foreground and wellness-in-the-foreground perspectives within that liminal space.

In my description of the practice of spiritual direction in Chapter Four, I noted that although the content would vary, a session would typically begin and end with ritual practices, such as lighting a candle, ringing a bell, sitting in silence, and/or saying a prayer. These ceremonial practices establish the boundaries of the spiritual direction session as an experience set apart from everyday life, an experience where director and directee focus solely on the directee's relationship with God/the transcendent. Simple yet deliberate acts imbue spiritual direction with a sacred quality. They also present an opportunity to help directees with chronic illnesses manage shifts between illness-in-the-foreground and wellness-in-the-foreground perspectives and help strengthen boundaries between WITF and IITF for women who experience IITF in problematic ways (such as chronically functioning out of a passive sick role or feeling overwhelmed by their disease).

To illustrate what an opening/closing ritual for perspective shifts might look like, I return to Mary and Jane. When Jane asks Mary if she has concerns related to discussing her illnesses, Mary says she is grateful for spiritual direction as a context in which she can talk about the spiritual dimension of her illness experiences, but she is anxious that illness experiences will also dominate another part of her life. Jane proposes that the women construct an opening and closing ritual to help establish boundaries for illness experiences in their spiritual direction sessions. After sitting in silence for several moments, seeking inspiration from God about a meaningful ritual for this purpose, the

women share the images and ideas that came to them. Eventually, the women's discussion coalesces around the image of containing Mary's illness experiences in a box that can be opened and closed at will. With that image in mind, they develop the following ritual.

Mary selects a small, plain cardboard box to symbolize her illness experiences related to lupus and Parkinson's disease. The box is small enough to fit in Mary's purse so that she can easily bring it to their spiritual direction sessions, and its size reinforces the notion that Mary and God are bigger than these diseases. At the beginning of their spiritual direction sessions, Jane offers a prayer for God's protection around them as Mary opens up about her illnesses. Mary then ceremoniously opens the box and places it between the women, symbolically indicating that the contents of the box are now available for reflection and discernment with God in this spiritual direction session. The women hold no expectation about what might or might not come out of the box in that session, but they have explicitly created a safe and sacred space, in the presence of God, for Mary to explore her illness experiences, especially in terms of her relationship with God. At the end of the session, the two women replace the lid on the box while Jane audibly affirms that illness experiences are but one dimension of Mary's life and can be appropriately contained. Jane also reminds Mary that God safely holds both Mary and her illness experiences. During the first few months of performing the closing ritual, Mary asks Jane to close the box with her. Soon Mary feels empowered to close the box herself. For now, Mary has chosen a plain brown box, reinforcing the idea that her illness

experiences are neutral entities. Later she might adorn this box or select a new decorative box as a reminder that a positive wellness perspective contains her illness experiences.

This illustration is meant to be descriptive and not prescriptive; every woman and her spiritual director should construct opening and closing rituals (or choose not to do so) that are meaningful and helpful for that directee at that time. The salient points embedded within the illustration are that IITF and WITF perspective shifts will occur during a woman's experience of autoimmune disease, but she and her spiritual director can recognize and cope effectively with life-limiting aspects of IITF periods using ritual that invokes Mary's sense of partnering with God in her spiritual and illness experiences. Inducing a controlled IITF experience at the beginning of the spiritual direction session can make illness experiences available for reflection without allowing illness to dominate. A temporary shift to IITF at the beginning of the session is accompanied by restoration of a WITF perspective at the end of the spiritual direction encounter. If this shift is not possible, the ritual could serve as a symbolic shift to this hoped-for reality.

The closing ritual symbolizes the creation or renewal of an ideal world in which the woman relies on her relationship with God/the transcendent to be able to return to a wellness-in-the-foreground perspective after IITF messages have been addressed (e.g., after she manages her pain or acknowledges losses). The memory of the closing act may later remind her that illness experiences are one dimension of her life, a life fully experienced when wellness is in the foreground (Bell, 1989, pp. 35-41; Smith, 1980, pp. 125-127).

Because they are already often ritualized, the opening and closing moments of spiritual direction are particularly conducive to rituals related to shifting perspectives. Ritual-making and performance that invoke the directee's sense of the presence of God/the transcendent can provide a measure of control when life feels overwhelming (Smith, 1980, p. 124), such as life within the ultimately uncontrollable liminal space of chronic illness. The remainder of the spiritual direction encounter is ripe with opportunities for other ritual-making work, including rituals to acknowledge and grieve disenfranchised losses.

#### **Acknowledging disenfranchised losses.**

In Chapter Three, I made a provisional theological claim that, particularly when illness is in the foreground, women with autoimmune diseases need to share their experiences of loss and have their losses publicly acknowledged to limit or alleviate disenfranchisement. I propose that public lament of losses, heard and clearly acknowledged by attentive and compassionate spiritual directors (and other directees in the case of group spiritual direction), can help women grieve losses associated with RA, MS, and lupus. Lament does not necessarily need to take place within the context of a ritual practice. However, lament is often included as an important element of women's ritual work, some women benefit from more formalized permission to express anger or deep sorrow (Berry, 2009, p. 76), and pastoral theologians and psychologists agree that ritual can be a powerful means of acknowledging disenfranchised losses (e.g., Anderson & Foley, 1998; Doka, 1989a, pp. 331-332; 2002b; Hogue, 2003). In addition, some



women may need to construct understandings of God/the transcendent that support lament and enable them to experience God/the transcendent as being with them in their suffering, and ritual can facilitate that constructive work.

Outside of ritual activity, an informed spiritual director might simply ask a directee to reflect on her losses. In this scenario, it is important that the spiritual director listen attentively to the woman's lament and acknowledge the loss in a way that clearly communicates to the directee that her suffering has been recognized and validated. This acknowledgement can consist of a few words, but should not be neglected (Mitchell & Anderson, 1983, p. 118; Montgomery, 2003). That said, spiritual directors should not underestimate the potential for ritual to empower women in ways that transcend narrative means of "being heard."

Recall that the definition of ritual I am using includes practices that integrate thought and action in order to help realize the ideals, hopes, values, and beliefs of a group. This dimension of ritual provides a means for women to perform (within the ritual ceremony) and live out (beyond the spiritual direction session) the changes they would like to see in the world, such as the acknowledgment of losses by members of their family or restoration of self-agency over their bodies (Berry, 2009, p. 94). This type of ritual practice may be most effective within a group model of spiritual direction because the benefits of ritual construction and performance are amplified by a larger group of women who support each other in resisting oppressive social discourses that contribute to disenfranchised losses (as elaborated in Chapter Two). I illustrate how Mary and Jane, in their one-on-one spiritual direction relationship, might construct a ritual that

acknowledges disenfranchised losses and supports Mary as she lives with chronic illness in new ways.

During their first few spiritual direction sessions, Jane encouraged Mary to name losses incurred with lupus and Parkinson's disease. Mary identified a variety of losses, including loss of control over her body and loss of time spent on pleasurable activities like gardening. With further reflection, Mary realized she was most troubled by two losses in particular: the loss of her "perfect" life and the loss of her childhood image of God as just ruler over creation. Mary was generally uncomfortable talking about these losses because she believed other people in her life were secretly pleased that she had to change in these ways. Mary's husband and mother both chided her for what they perceived to be unhealthy perfectionist tendencies. Her father, who had been physically abused as a boy by his alcoholic father, scoffed at Mary's beliefs that God was in control of anything, especially the appropriation of justice. Mary had described lupus as chaos, and her losses were part of that chaotic experience that she wished to contain. Mary and Jane agreed to hold the images of chaos and containment in their minds as they sat in silence, seeking insight from God on how they might ritually acknowledge Mary's losses. Out of their contemplative reflections they co-constructed the following ritual.

Mary purchased two small mirrors from the craft store. One mirror symbolized the "perfect" reflection that Mary always hoped to see of herself; the other mirror symbolized the "perfect" image Mary held of a just God. During a spiritual direction session dedicated to the performance of this ritual, the women placed the mirrors on a tray, noting their symbolic significance to Mary. Jane covered each mirror with a piece of

black cloth, Mary's chosen symbol for the way lupus and Parkinson's disease appeared in her life and obscured her vision of these images. Then Mary shattered the mirrors with a hammer.

The women removed the cloths and explicitly asked for God's guidance as they spent time reflecting on the broken pieces of mirror. After their silence, Mary described how she felt physically shattered by the pain of lupus and spiritually shattered by the impact of her illness experiences on the long-held images of herself and God. Mary also noted that the shattered glass created a chaotic image, but the image also retained a sense of structure, affirming Mary's recent narrative theological meaning making around chaos theory. At the end of their time together, Jane affirmed Mary's observations, her suffering, and the importance of the losses Mary had experienced. Jane offered a prayer that acknowledged losses spoken and unspoken, and she expressed her hope that, with God's continued guidance, both women would have further insights into Mary's illness experiences. Mary collected the pieces of mirror to take home with her, and Jane rang a bell to signal a formal end to the ritual performance. The women agreed to share their ongoing reflections about the ritual at their next session.

Jane and Mary's performance of and reflection on the ritual acknowledged the reality of Mary's losses in tangible ways, including the sounds of shattering glass and the visual reality of the broken mirrors. The broken pieces of glass reinforced Mary's (more tentative) and Jane's (much firmer) beliefs that although Mary's images of herself and God had changed, they had not been completely destroyed. The ritual also resonated with

and enacted the chaos theory narrative meaning making work the women had done together.

After the spiritual direction session, Mary continued to seek insight from God on how this ritual could offer new insights into her illness experiences and help her heal from them. After a few days, Mary realized she wanted to use the broken pieces of mirror to create something functional and beautiful out of her shattering experiences. She covered the tray used in the ritual with the broken pieces of mirror, gluing them in place to creating a mosaic pattern. This act was not formally planned, but the women might consider it an extension of the ritual because it occurred during their agreed-upon ongoing reflection time, or they might consider it to be the construction of a new, private ritual that Mary performed on her own to continue her healing process. The tray helped concretize Mary's narrative reconstruction work as she physically created a new structure from the chaotic shards of shattered glass. The next month, when she met Jane for another session of spiritual direction, Mary brought the tray, now a symbol of how the illness experiences that have affected her life are being transformed. The tray also represents the changes Mary wants to see in the future: images of God and self, reflected in new ways that are no longer "perfect," and it symbolizes order arising out of chaotic illness experiences.

Mary and Jane designed this ritual as a one-time performance, but the women might feel the need to repeat the ritual at another time or reconstruct it in ways that acknowledge new losses. This mirror ritual was appropriate for Mary's experiences, and it might be adapted for other individuals or for groups of women, if they find the

symbolism meaningful. Rituals need to be contextual, but they do not need to be completely original. It is acceptable to translate existing rituals into new contexts as long as the participants are involved in the decision-making and planning processes (Hogue, 2003, pp. 123-125).

When they were constructing the ritual, the women discussed the possibility of inviting other people to witness it, but Mary chose to share the experience only with Jane in the presence of God. However, after she created the mirrored tray, Mary discovered that it served as a tangible symbol of her illness experiences that helped other people recognize the reality and magnitude of her losses. Using the tray as a focus for conversation, Mary was able to talk about the ritual and her losses with her husband and mother, establishing another public witness for her experiences. As she did this, Mary invited other people to “observe” the ritual; she just did so in a way that offered her control of how much or how little of the experience she revealed. Other women might wish to include participants and/or observers more directly in their ritual experiences, and these people could be invited to attend a special spiritual direction session specifically for this ritual work.

As I noted in Chapter Four, the model described in the case study with Mary and Jane represents one-on-one spiritual direction. However, group spiritual direction could also incorporate the elements of this model and provide additional benefits to women who have autoimmune diseases (as described in Chapter Four).

## **A Model of Spiritual Direction Summarized**

In this chapter, I described elements of a model of spiritual direction for the growing number of women who have rheumatoid arthritis, multiple sclerosis, and systemic lupus erythematosus. Practices such as intercultural spiritual care, lament, complex theological meaning making, narrative co-construction, attention to coping strategies and spiritual practices, and ritual work are not particular to spiritual direction and are used in other caregiving settings for any number of purposes. Two features set apart this approach to psychospiritual care from other caregiving approaches: (1) the integration of these care strategies within the unique context of spiritual direction, a practice that supports long-term relationships and is explicitly focused on a person's relationship with God/the transcendent, and (2) the contextual use of these practices to address the psychospiritual needs of women who have autoimmune diseases. As a complementary approach to biomedical care for the physiological dimension of autoimmune diseases, spiritual direction offers what no other caregiving approach can provide to meet the psychospiritual needs of women with autoimmune conditions in these ways.

A model of spiritual direction for women with autoimmune diseases is described in the following guidelines. A specific plan of action (such as the manualized treatment protocols commonly used in psychotherapy) would be antithetical to the highly contextual practice of spiritual direction. Rather, spiritual directors equip themselves with knowledge about various populations, approaches to care, and spiritual disciplines in order to effectively companion careseekers from diverse backgrounds (e.g., Hansen,

Mabry, & Williams, 2003; Hawthorne, 2006; Ruffing, 2006). This model of spiritual direction provides the structural support needed to address the psychospiritual needs of women who have RA, MS, and lupus without infringing on the contextual nature of the unique long-term, narrative, collaborative, and contextual relationship among spiritual director, directee, and God/the transcendent. I also have not stipulated that a spiritual director using this model of care needs to be a woman. The choice of spiritual director is a personal decision that may take into account a number of factors, including location, social identity, and an intuitive sense of connection between two people. The choice of spiritual director remains at the discretion of individual directees. The model integrates the following five elements into the contemporary practice of spiritual direction grounded in the historical Christian tradition: informed spiritual directors, an intercultural and feminist approach to care, complex and contextual meaning making, attention to coping strategies and spiritual practices, and rituals that negotiate shifting perspectives and acknowledge losses.

### **Informed spiritual directors.**

Spiritual directors working with women who have RA, MS, or lupus should be informed about women's experiences of autoimmune disease, such as the rich description found in Chapter Two of this dissertation. Spiritual directors should be aware that women who experience ongoing suffering and losses (which are often disenfranchised) are at greater risk of getting stuck in spiritual struggles that can negatively affect their health and well-being. Informed spiritual directors can balance a woman's needs to engage in

transformative spiritual struggles with the risks posed by getting stuck in life-diminishing chronic struggles. Spiritual directors also need to be cognizant of the liminal nature of chronic illness, experienced as ongoing shifts between illness-in-the-foreground and wellness-in-the-foreground perspectives, and how this liminal reality affects a woman's ability to sustain a well-integrated spirituality and her relationship with God/the transcendent.

### **Intercultural and feminist approach to care.**

This model of spiritual direction engages in long-term exploration of women's experiences and understandings of God/the transcendent and chronic illness using an intercultural and feminist approach to care which privileges directees' accounts and meaning making. Intercultural spiritual care makes explicit the practice of not-knowing that is embedded in spiritual direction in the Christian tradition. This feminist approach to care validates women's experiences and empowers women over and over again as they resist oppressive social discourses that affect their ongoing illness experiences in life-diminishing ways.

### **Complex and contextual meaning making.**

Spiritual directors working with women who have RA, MS, or lupus need to facilitate ongoing, complex, constructive, and contextual theological meaning making that takes into account the unique psychospiritual needs of this population. Using narrative and ritual practices, directors and directees can collaborate with God/the



transcendent in life-enhancing ways in times of illness-in-the-foreground and in times of wellness-in-the-foreground. Meaning making in this context should include recurring opportunities for lament, and it should engage diverse theological understandings of illness, disability, and suffering—such as theologies described by Creamer (2009), Eiesland (1994), and Nelson (2003)—in order to help directees reconstruct their understandings of and sustain their relationships with God/the transcendent throughout years of living with degenerative health conditions.

**Attention to coping strategies and spiritual practices.**

Spiritual directors and directees, in collaboration with God/the transcendent, should reinforce life-enhancing theological understandings through the directees' lived coping strategies and spiritual practices. Given the long-term nature of both chronic illness and spiritual direction, theological meaning making will be an ongoing process. The conservation and transformation of coping strategies and spiritual practices that enact changing understandings of God/the transcendent, illness, and suffering will also be ongoing collaborative and contextual work.

**Rituals to negotiate shifting perspectives and acknowledge losses.**

In this model of spiritual direction, directors should be equipped to co-construct and perform contextual rituals that invoke a directee's understandings of God/the transcendent in relationship to her illness experiences. Rituals should draw on a directee's spirituality as they facilitate life-enhancing transitions between illness-in-the-foreground

and wellness-in-the-foreground perspectives (e.g., in opening and closing moments of the spiritual direction session) and as they acknowledge ongoing and potentially disenfranchised losses.

## **The Future**

This dissertation informs pastoral/spiritual, psychological, and medical caregivers with an interdisciplinary and multi-dimensional understanding of women's experiences of living with RA, MS, and lupus. In my description of autoimmune diseases from a woman's perspective, I named categories of disenfranchised losses often experienced by women with these conditions. This work increases the breadth of psychological and pastoral theological understandings of disenfranchised loss that focus on death and bereavement. The potential for disenfranchised losses extends beyond autoimmune diseases to chronic illnesses more broadly, and this dissertation adds to understandings of the potential psychospiritual ramifications of ongoing health conditions in general.

The long-term nature of both chronic illness and spiritual direction creates a challenging but potentially rewarding context for future research on the effectiveness of the proposed model of care and other approaches to healing for women with chronic conditions. To begin this work, multi-disciplinary participants need to address definitions of *spirituality* and adopt or develop appropriate research methods for spiritual direction (and spirituality in general) that ensure potential research would prove credible for medical, psychological, and spiritual researchers, scholars, and care providers.

The explicitly feminist and intercultural model of care described here fills a need for practical approaches to spiritual care that privilege women's experiences and beliefs. A particularly important element of this practical model is caregiver reflection on the ways in which people understand illness and disability. People's attributions of illness causation have the potential to limit the effectiveness of care in any context when strategies for care reinforce life-limiting beliefs or work against life-enhancing understandings of illness. The importance of caregiver self-awareness of their own beliefs about illness and disability is critical when helping people who have acute and chronic health conditions. Care providers in all contexts uncritically impose their beliefs on these careseekers every day, and this power dynamic affects caregiving relationships and the careseeker's healing process in ways we have yet to fully understand.

Certainly, spiritual direction will not appeal to all women with autoimmune diseases, although women frequently rely on spiritual coping strategies, particularly when they have exhausted other coping resources. Making practices such as this model of spiritual direction available to women is a concern. As is true of other spiritual caregiving approaches,<sup>7</sup> the potential for fees charged by some spiritual directors (typically in the range of \$40-100 per hour) may put this type of care out of reach for many women who could benefit from it. However, not all spiritual directors charge fees, and others offer sliding payment scales to meet the needs of women in different financial circumstances. These groups of directors might be most appropriate for women with a limited ability to pay for psychospiritual care in addition to expensive biomedical treatments and services.

---

<sup>7</sup> Spiritual direction, like many other complementary and alternative therapies (CAM), is not a treatment option covered by health insurance.

The portability of spiritual direction (i.e., sessions can be held over the phone or through on-line exchanges using e-mail or social networking sites) can help overcome other access issues, including geographic distance between directors and directees and the potential for women with chronic health conditions to have difficulty traveling to/from spiritual direction sessions.

We lack a complex public theology of chronic illness that extends beyond moral understandings of pain and suffering, understandings that are often life-limiting to women with chronic conditions. This dissertation contributes to the important task of developing a public theology<sup>8</sup> of chronic illness through its rich description of a woman's experience of autoimmune disease; constructive theological claims about the psychospiritual needs of women who have RA, MS, and lupus; and proposal of a practical strategy that helps women heal and sustain their relationships with God/the transcendent in the midst of ongoing losses and suffering.

Ideally, pastoral theologians and spiritual directors will work together to develop a public theology of chronic illness. Spiritual directors engaged in spiritual direction with directees who have chronic health conditions should remain accountable to the greater spiritual care community by contributing their experiences toward more sophisticated understandings of psychospiritual dimensions of chronic health conditions. Today this work takes place through articles published in *Presence: An International Journal of*

---

<sup>8</sup>The pastoral theological task of developing public theology includes “identifying, evaluating, and modifying the technical practices, core meaning systems, and normative value structures operating within and between all of the efforts of care brought to bear upon individuals and groups within our common life. To accomplish its task, pastoral theology develops for public debate and policy interpretations of our common life, norms by which this life will be lived, and practical strategies for healing, sustaining, guiding, and liberating individuals, culture, and the natural order” (L. K. Graham, 2000, p. 12; see also Miller-McLemore, 2004).

*Spiritual Direction* and through conversations about spiritual direction with health care providers (e.g., Puchalski et al., 2009). Now is the time to also engage pastoral theologians in that dialogue.

My personal illness experience of living with autoimmune disease, my relationships with other women who have these disorders, and my relationship with my spiritual director provided the impetus for this dissertation. Using medical and psychological literature, I added to these experiences the stories of many other people with autoimmune disorders in order to describe what life is like for women who have these degenerative and incurable diseases. The story of Mary and her spiritual director Jane helped illuminate how a model of contemplative intercultural spiritual direction offers a narrative, contextual, and collaborative approach to care that focuses on a woman's relationship with God/the transcendent in ways that meet the unique psychospiritual needs of women who have RA, MS, and lupus. It is my hope that this reflective, analytical, and constructive conversation about spiritual direction and chronic illness will encourage further interdisciplinary discussions and development of collaborative approaches to holistic care for women with autoimmune diseases and, eventually, for women *and* men who live with a variety of chronic health conditions.

## References

- Abraham, J. (1989). The clergy and the disenfranchised. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 249-256). Lexington, MA: Lexington Books.
- Achterberg, J., Dossey, B., & Kolkmeier, L. (1994). *Rituals of healing: Using imagery for health and wellness*. New York: Bantam Books.
- Addison, H. A. (2004). Reciprocal grace: The vocabulary of Jewish spiritual direction. *Presence: An International Journal of Spiritual Direction*, 10(1), 28-32.
- Affleck, G., Pfeiffer, C., Tennen, H., & Fifield, J. (1987). Attributional processes in rheumatoid arthritis patients. *Arthritis and Rheumatism*, 30, 927-931.
- Agrimson, L. B., & Taft, L. B. (2008). Spiritual crisis: A concept analysis. *Journal of Advanced Nursing*, 65(2), 454-461. doi: 10.1111/j.1365-2648.2008.04869.x
- Aguilar, N. (1997). Counseling the patient with chronic illness: Strategies for the health care provider. *Journal of the American Academy of Nurse Practitioners*, 9(4), 171-175.
- Alsaker, S., Bongaardt, R., & Josephsson, S. (2009). Studying narrative-in-action in women with chronic rheumatic conditions. *Qualitative Health Research*, 19(8), 1154-1161. doi: 10.1177/1049732309341478
- Anderson, H. (2001). Spiritual care: The power of an adjective. *Journal of Pastoral Care*, 55(3), 233-237.
- Anderson, H., & Foley, E. (1998). *Mighty stories, dangerous rituals: Weaving together the human and the divine*. San Francisco, CA: Jossey Bass.
- Anonymous. (trans. 1981). *The cloud of unknowing*. Mahwah, NJ: Paulist Press.
- Arora, K. R. (2005). *A contemporary model of spiritual direction by e-mail based on the letters of Baron Friedrich von Hügel*. Church History. (Unpublished master's thesis). Memphis Theological Seminary. Memphis, TN.
- Arora, K. R. (in press). Not-knowing in spiritual direction: Reflections on social identity. *Presence: An International Journal of Spiritual Direction*.
- Arvay, M. J. (2001). Shattered beliefs: Reconstituting the self of the trauma counselor. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 213-230). Washington, DC: American Psychological Association.

- Astin, J. A., Beckner, W., Soeken, K., Hochberg, M. C., & Berman, B. (2002). Psychological interventions for rheumatoid arthritis: A meta-analysis of randomized controlled trials. *Arthritis and Rheumatism*, 47(3), 291–302. doi: 10.1002/art.10416
- Athanasius. (trans. 1980). *The life of Antony* (R. C. Gregg, Trans.). San Francisco, CA: HarperSanFrancisco.
- Attig, T. (2001). Relearning the world: Making and finding meanings. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 33-53). Washington, DC: American Psychological Association.
- Autoimmune disease in women. (2010). Retrieved from [http://www.aarda.org/women\\_and\\_autoimmunity.php](http://www.aarda.org/women_and_autoimmunity.php)
- Ávila, T. (trans. 1961). *Interior castle* (E. A. Peers, Trans.). New York, NY: Image Books.
- Badaracco, C. H. (2007). *Prescribing faith: Medicine, media, and religion in American culture*. Waco, TX: Baylor University Press.
- Barbour, I. G. (2000). *When science meets religion*. New York, NY: HarperCollins.
- Barnes, P. M., Bloom, B., & Nahin, R. L. (2008). *Complementary and alternative medicine use among adults and children: United States, 2007*. Hyattsville, MD: National Center for Health Statistics.
- Barrett, J. (1995). Multiple sclerosis: The experience of a disease. *Women's Studies International Forum*, 18(2), 159-171.
- Barry, W. A., & Connolly, W. J. (1982). *The practice of spiritual direction*. San Francisco, CA: HarperSanFrancisco.
- Bartel, M. (2004). What is spiritual? What is spiritual suffering? *Journal of Pastoral Care and Counseling*, 58(3), 187-201.
- Bartlett, S. J., Piedmont, R., Bilderback, A., Matsumoto, A. K., & Bathon, J. M. (2003). Spirituality, well-being, and quality of life in people with rheumatoid arthritis. *Arthritis and Rheumatism (Arthritis Care and Research)*, 49(6), 778-783. doi: 10.1002/art.11456
- Beck, M. (2007). Illness, disease and sin: The connection between genetics and spirituality. *Christian Bioethics*, 13, 67-89. doi: 10.1080/13803600701283052
- Becker, G. (1999). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley, CA: University of California Press.

- Bediako, S. M., & Friend, R. (2004). Illness-specific and general perceptions of social relationships in adjustment to rheumatoid arthritis: The role of interpersonal expectations. *Annals of Behavioral Medicine, 28*(3), 203-210.
- Bell, C. (1987). Discourse and dichotomies: The structure of ritual theory. *Religion 17*, 95-118.
- Bell, C. (1989). Ritual, change, and changing rituals. *Worship, 63*(1), 31-41.
- Berry, J. (2009). *Ritual making women: Shaping rites for changing lives*. London, England: Equinox Publishing Ltd.
- Betcher, S. V. (2001). Rehabilitating religious discourse: Bringing disability studies to the theological venue. *Religious Studies Review, 27*(4), 341-348.
- Bidwell, D. R. (2004a). Real/izing the sacred: Spiritual direction and social constructionism. *Journal of Pastoral Theology, 14*(1), 59-74.
- Bidwell, D. R. (2004b). *Short-term spiritual guidance*. Minneapolis, MN: Fortress.
- Black, K. (1996). *A healing homiletic: Preaching and disability*. Nashville, TN: Abingdon Press.
- Block, J. W. (2002). *Copious hosting: A theology of access for people with disabilities*. New York, NY: Continuum.
- Bloomfield, H. (1989). The healing silence. In R. Carlson & B. Shield (Eds.), *Healers on Healing* (pp. 177-178). New York, NY: Putnam Publishing.
- Bolletino, R. C. (2001). A model of spirituality for psychotherapy and other fields of mind-body medicine. *Advances in Mind-Body Medicine, 17*(2), 90-101, 104-107.
- Boss, P., & Couden, B. A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples and families. *Psychotherapy in Practice, 58*(11), 1351-1360. doi: 10.1002/jclp.10083
- Brannon, L., & Feist, J. (2010). *Health psychology: An introduction to behavior and health* (7th ed.). Belmont, CA: Wadsworth, Cengage Learning.
- Bregman, L. (2004). Defining spirituality: Multiple uses and murky meanings of an incredibly popular term. *Journal of Pastoral Care and Counseling, 58*(3), 157-167.
- Buddhist scriptures*. (trans. 1987). (E. Conze, Trans.). London, England: Penguin Books Ltd.



- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182.
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health and Illness*, 13(4), 451-468.
- Bush, E. G., Rye, M. S., Brant, C. R., Emery, E., Pargament, K. I., & Riessinger, C. A. (1999). Religious coping with chronic pain. *Applied Psychophysiology and Biofeedback*, 24(4), 249-260.
- Byrne, L. (1990). *Traditions of spiritual guidance*. Collegeville, MN: Liturgical Press.
- Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 157-172). Washington, DC: American Psychological Association.
- Cassell, D. K., & Rose, N. R. (2003). *The encyclopedia of autoimmune diseases*. New York, NY: Facts on File.
- Cassell, E. J. (2004/1991). *The nature of suffering and the goals of medicine* (2nd ed.). New York, NY: Oxford University Press.
- Cassian, J. (trans. 1997). *John Cassian: The conferences* (B. Ramsey, Trans.). New York, NY: Newman Press.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680.
- Chittister, J. (2003). *The rule of Benedict: Insights for the ages*. New York, NY: Crossroad.
- Chronic disease fact sheet. (2008). Retrieved from Partnership to Fight Chronic Disease <http://www.fightchronicdisease.org/resources/chronic-disease-fact-sheet>
- Clarke, J. (2009). A critical view of how nursing has defined spirituality. *Journal of Clinical Nursing*, 18(12), 1666-1673. doi: 10.1111/j.1365-2702.2008.02707.x
- Cohen, E. (2004). My self as an other: On autoimmunity and "other" paradoxes. *Medical Humanities*, 30, 7-11. doi: 10.1136/jmh.2004.000162
- Cohen, M. H. (2006). *Healing at the borderland of medicine and religion*. Chapel Hill, NC: University of North Carolina Press.

- Cole, B. S., & Pargament, K. I. (1999a). Re-creating your life: A spiritual/psychotherapeutic intervention for people diagnosed with cancer. *Psycho-Oncology*, 8, 395-407.
- Cole, B. S., & Pargament, K. I. (1999b). Spiritual surrender: A paradoxical path to control. In W. R. Miller (Ed.), *Integrating spirituality into treatment: Resources for practitioners* (pp. 179-196). Washington, DC: American Psychological Association.
- Compston, A., & Coles, A. (2002). Multiple sclerosis. *Lancet*, 359, 1221-1231.
- Cooper-White, P. (2004). *Shared wisdom: Use of the self in pastoral care and counseling*. Minneapolis, MN: Fortress Press.
- Coruh, B., Ayele, H., Pugh, M., & Mulligan, T. (2005). Does religious activity improve health outcomes? A critical review of the recent literature. *Explore (NY)*, 1(3), 186-191. doi: 10.1016/j.explore.2005.02.001
- Crawford, S. J. (2006). Religion, healing, and the body. In L. L. Barnes & I. Talamantez (Eds.), *Teaching religion and healing* (pp. 29-45). New York, NY: Oxford University Press.
- Creamer, D. B. (2009). *Disability and Christian theology: Embodied limits and constructive possibilities*. New York, NY: Oxford University Press.
- Crislip, A. T. (2005). *From monastery to hospital: Christian monasticism and the transformation of health care in late antiquity*. Ann Arbor, MI: University of Michigan Press.
- Cross, S. J. (trans. 1959). *Dark night of the soul* (E. A. Peers, Trans.). New York, NY: Image Books.
- Curlin, F. A., Chin, M. H., Sellergren, S. A., Roach, C. J., & Lantos, J. D. (2006). The association of physicians' religious characteristics with their attitudes and self-reported behaviors regarding religion and spirituality in the clinical encounter. *Medical Care*, 44(5), 446-453.
- Dale, H., & Hunt, N. (2008). Perceived need for spiritual and religious treatment options in chronically ill individuals. *Journal of Health Psychology*, 13(5), 712-718. doi: 10.1177/1359105308094589
- Danoff-Burg, S., & Friedberg, F. (2009). Unmet needs of patients with systemic lupus erythematosus. *Behavioral Medicine*, 35, 5-13.

- Davis, C. G. (2001). The tormented and the transformed: Understanding responses to loss and trauma. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 137-155). Washington, DC: American Psychological Association.
- Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, *75*(2), 561-574.
- Definition of autoimmune disease. (2008). Retrieved from [http://autoimmune.pathology.jhmi.edu/whatis\\_disease.cfm](http://autoimmune.pathology.jhmi.edu/whatis_disease.cfm)
- Devins, G. M., & Seland, T. P. (1987). Emotional impact of multiple sclerosis: Recent findings and suggestions for future research. *Psychological Bulletin*, *101*(3), 363-375.
- DiLorenzo, T. A., Becker-Feigeles, J., Halper, J., & Picone, M. A. (2008). A qualitative investigation of adaptation in older individuals with multiple sclerosis. *Disability and Rehabilitation*, *30*(15), 1088-1097. doi: 10.1080/09638280701464256
- Dixon, K. E., Keefe, F. J., Scipio, C. D., Perri, L. M., & Abernethy, A. P. (2007). Psychological interventions for arthritis pain management in adults: A meta-analysis. *Health Psychology*, *26*(3), 241-250. doi: 10.1037/0278-6133.26.3.241
- Doehring, C. (1992). Developing models of feminist pastoral counseling. *Journal of Pastoral Care and Counseling*, *46*(1), 23-31.
- Doehring, C. (1999). A method of feminist pastoral theology. In B. J. Miller-McLemore & B. Gill-Austern (Eds.), *Feminist and womanist pastoral theology* (pp. 95-112). Nashville, TN: Abingdon.
- Doehring, C. (2009). Theological accountability: The hallmark of pastoral counseling. *Sacred Spaces: The e-Journal of the American Association of Pastoral Counselors*, *1*(1).
- Doehring, C. (2010). *The practice of spiritual care: An intercultural approach*. Denver, CO.
- Doka, K. J. (1989a). Conclusion. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 329-333). Lexington, MA: Lexington Books.
- Doka, K. J. (1989b). Professional Perspectives. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 239-240). Lexington, MA: Lexington Books.

- Doka, K. J. (2002a). Preface. In K. J. Doka (Ed.), *Disenfranchised grief: new directions, challenges, and strategies for practice* (pp. xiii-xv). Champaign, IL: Research Press.
- Doka, K. J. (2002b). The role of ritual in the treatment of disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges and strategies for practice* (pp. 135-147). Champaign, IL: Research Press.
- Doka, K. J. (2009). *Counseling individuals with life-threatening illness*. New York, NY: Springer Publishing.
- Doka, K. J., & Aber, R. A. (2002). Psychosocial loss and grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges and strategies for practice* (pp. 217-231). Champaign, IL: Research Press.
- Doka, K. J., & Martin, T. L. (2002). How we grieve: Culture, class, and gender. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 337-347). Champaign, IL: Research Press.
- Dougherty, R. M. (1995). *Group spiritual direction: Community for discernment*. New York, NY: Paulist Press.
- Douglas, C., Windsor, C., & Wollin, J. (2008). Understanding chronic pain complicating disability: Finding meaning through focus group methodology. *Journal of Neuroscience Nursing*, 40(3), 158-168.
- Druley, J. A., Stephens, M. A. P., & Coyne, J. C. (1997). Emotional and physical intimacy in coping with lupus: Women's dilemmas of disclosure and approach. *Health Psychology*, 16(6), 506-514.
- Dubouloz, C.-J., Laporte, D., Hall, M., Ashe, B., & Smith, C. D. (2004). Transformation of meaning perspectives in clients with rheumatoid arthritis. *American Journal of Occupational Therapy*, 58(4), 398-407.
- Duval, M. L. (1984). Psychosocial metaphors of physical distress among MS patients. *Social Science and Medicine*, 19(6), 635-638.
- Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliative Medicine*. Retrieved from <http://pmj.sagepub.com/content/early/2010/07/19/0269216310375860>  
doi:10.1177/0269216310375860
- Edwards, T. (1980). *Spiritual friend: Reclaiming the gift of spiritual direction*. New York, NY: Paulist Press.

- Edwards, T. (2001). *Spiritual director, spiritual companion: Guide to tending the soul*. New York, NY: Paulist Press.
- Egnew, T. R. (2005). The meaning of healing: Transcending suffering. *Annals of Family Medicine* 3(3), 255-262. doi: 10.1370/afm.313
- Eiesland, N. L. (1994). *The disabled God: Toward a liberatory theology of disability*. Nashville, TN: Abingdon.
- Eilberg, A. (2005). Jewish theologies of spiritual direction. *Presence: An International Journal of Spiritual Direction*, 11(3), 28-32.
- Eisenberg, D. M., Kessler, R. C., Van Rompay, M. I., Kaptchuk, T. J., Wilkey, S. A., Appel, S., & Davis, R. B. (2001). Perceptions about complementary therapies relative to conventional therapies among adults who use both: Results from a national survey. *Annals of Internal Medicine*, 135(5), 344-351.
- Eklund, V., & MacDonald, M. L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology: Research and Practice*, 22(4), 277-284.
- Ellis, M. R., & Campbell, J. D. (2004). Patients' views about discussing spiritual issues with primary care physicians. *Southern Medical Journal*, 97(12), 1158-1164.
- Faull, K., & Hills, M. D. (2006). The role of the spiritual dimension of the self as the prime determinant of health. *Disability and Rehabilitation* 28(11), 729-740. doi: 10.1080/09638280500265946
- Finan, P., Zautra, A. J., & Tennen, H. (2008). Daily diaries reveal influence of pessimism and anxiety on pain prediction patterns. *Psychology and Health*, 23(5), 551-568. doi: 10.1080/08870440802108892
- Fischer, K. (1988). *Women at the well: Feminist perspectives on spiritual direction*. New York, NY: Paulist.
- Fishbain, D. A., Hall, J. A., Risser, R. C., & Gonzales, J. S. (2009). Does pain cause the perception of fatigue in patients with chronic pain? Findings from studies for management of diabetic peripheral neuropathic pain with duloxetine. *Pain Practice*, 9(5), 354-362. doi: 10.1111/j.1533-2500.2009.00294.x
- Fitchett, G., Murphy, P. E., Kim, J., Gibbons, J. L., Cameron, J. R., & Davis, J. A. (2004). Religious struggle: Prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. *International Journal of Psychiatry in Medicine*, 34(2), 179-196.

- Fitchett, G., & Risk, J. L. (2009). Screening for spiritual struggle. *Journal of Pastoral Care and Counseling*, 63(1-2).
- Fong, T., Finlayson, M., & Peacock, N. (2006). The social experience of aging with a chronic illness: Perspectives of older adults with multiple sclerosis. *Disability and Rehabilitation*, 28(11), 695-705. doi: 10.1080/09638280500277495
- Freeman, A. (1998). Spirituality, well-being, and ministry. *Journal of Pastoral Care*, 52(1), 7-17.
- Gall, T. L., & Cornblat, M. W. (2002). Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment. *Psycho-Oncology*, 11, 524-535. doi: 10.1002/pon.613
- Gall, T. L., & Grant, K. (2005). Spiritual disposition and understanding illness. *Pastoral Psychology*, 53(6), 515-533. doi: 10.1007/s11089-005-4818-y
- Gerkin, C. V. (1984). *The living human document: Re-visioning pastoral counseling in a hermeneutical mode*. Nashville, TN: Abingdon.
- Giffords, E. D. (2003). Understanding and managing systemic lupus erythematosus (SLE). *Journal of Social Work in Health Care*, 37(4), 57-72. doi: 10.1300/J010v37n04\_04
- Glucklich, A. (2001). *Sacred pain: Hurting the body for the sake of the soul*. New York, NY: Oxford University Press.
- Goodman, D., Morrissey, S., Graham, D., & Bossingham, D. (2005). Illness representations of systemic lupus erythematosus. *Qualitative Health Research*, 15(5), 606-619. doi: 10.1177/1049732305275167
- Gordon, P. A., Feldman, D., Crose, R., Schoen, E., Griffing, G., & Shankar, J. (2002). The role of religious beliefs in coping with chronic illness. *Counseling and Values*, 46, 162-174.
- Graham, E., Walton, H., & Ward, F. (2005). *Theological reflection: Methods*. London, England: SCM Press.
- Graham, L. K. (1992). *Care of persons, care of worlds: A psychosystems approach to pastoral care and counseling*. Nashville, TN: Abingdon.
- Graham, L. K. (2000). Pastoral theology as public theology in relation to the clinic. *Journal of Pastoral Theology*, 10, 1-17.

- Gray, K., & Wegner, D. M. (2010). Blaming God for our pain: Human suffering and the divine mind. *Personality and Social Psychology Review, 14*, 7-16. doi: 10.1177/1088868309350299
- Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2005). The impact of illness representations and disease activity on adjustment in women with rheumatoid arthritis: A longitudinal study. *Psychology and Health, 20*(5), 597-613. doi: 10.1080/14768320500094177
- Grytten, N., Glad, S. B., Aarseth, J. H., Nyland, H., Midgard, R., & Myhr, K. (2006). A 50-year follow-up of the incidence of multiple sclerosis in Hordaland County, Norway. *Neurology, 66*(2), 182-186. doi: 10.1212/01.wnl.0000195549.95448.b9
- Grytten, N., & Mäseide, P. (2005). "What is expressed is not always what is felt": Coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness, 1*(3), 231-243. doi: 10.1177/17423953050010030601
- Guenther, M. (1992). *Holy listening: The art of spiritual direction* Boston, MA: Cowley Publications.
- Haija, A. J., & Schulz, S. W. (2011). The role and effect of complementary and alternative medicine in systemic lupus erythematosus. *Rheumatic Disease Clinics of North American, 37*(1), 47-62.
- Hall, E. H., Meador, K. G., & Koenig, H. G. (2008). Measuring religiousness in health research: Review and critique. *Journal of Religion and Health, 47*, 134-163. doi: 10.1007/s10943-008-9165-2
- Hamilton-Poore, S., & Sullender, R. S. (2009). Psyche and soul: Dialogue at the crossroads of pastoral counseling and spiritual direction. *Presence: An International Journal of Spiritual Direction, 15*(1), 25-33.
- Hammerschlag, C. A., & Silverman, H. D. (1997). *Healing ceremonies: Creating personal rituals for spiritual, emotional, physical and mental health*. New York, NY: The Berkeley Publishing Group.
- Handzo, G., & Koenig, H. G. (2004). Spiritual care: Whose job is it anyway? *Southern Medical Journal, 97*(12), 1242-1244.
- Hansen, R., Mabry, J. R., & Williams, R. B. (2003). Companionship people with dementia. *Presence: An International Journal of Spiritual Direction, 9*(3), 45-54.
- Hanson, M. J. (1999). Bioethics and the challenge of theodicy. In M. E. Mohrmann & M. J. Hanson (Eds.), *Pain seeking understanding* (pp. 175-188). Cleveland, OH: The Pilgrim Press.

- Hart, T. (2007). What to expect in Christian spiritual direction. *Presence: An International Journal of Spiritual Direction*, 13(1), 39-44.
- Haugli, L., Strand, E., & Finset, A. (2004). How do patients with rheumatic disease experience their relationship with their doctors? A qualitative study of experiences of stress and support in the doctor–patient relationship. *Patient Education and Counseling*, 52, 169-174. doi: 10.1016/S0738-3991(03)00023-5
- Hawthorne, T. A. (2006). Spiritual direction for the bereaved: Grief, spiritual crises and dark nights of the soul. *Presence: An International Journal of Spiritual Direction*, 12(1), 35-42.
- Hays, J. (2010). *Queering Eiesland's Christ*. Paper presented at the American Academy of Religion, Religion and Disability Studies Group, Atlanta, GA.
- Hebert, R. S., Jenckes, M. W., Ford, D. E., O'Connor, D. R., & Cooper, L. A. (2001). Patient perspectives on spirituality and the patient-physician relationship. *Journal of General Internal Medicine*, 16(10), 685-692. doi: 10.1111/j.1525-1497.2001.01034.x
- Hilbert, R. A. (1984). The acultural dimensions of chronic pain: Flawed reality construction and the problem of meaning. *Social Problems*, 31(4), 365-378.
- Hiltner, S. (1958). *Preface to pastoral theology*. New York, NY: Abingdon.
- Hogue, D. A. (2003). *Remembering the future, imagining the past: Story, ritual, and the human brain*. Cleveland, OH: Pilgrim Press.
- Hsu, C., Phillips, W. R., Sherman, K. J., Hawkes, R., & Cherkin, D. C. (2008). Healing in primary care: A vision shared by patients, physicians, nurses, and clinical staff. *Annals of Family Medicine*, 6, 307-314. doi: 10.1370/afm.838
- Hunt, L. M., Jordan, B., & Irwin, S. (1989). Views of what's wrong: Diagnosis and patients' concepts of illness. *Social Science and Medicine*, 28(9), 945-956.
- IASP pain terminology. (2010). *IASP: Working Together for Pain Relief*. Retrieved from [http://www.iasp-pain.org/AM/Template.cfm?Section=Pain\\_Definitions&ContentID=1728#Pain](http://www.iasp-pain.org/AM/Template.cfm?Section=Pain_Definitions&ContentID=1728#Pain)
- Illis, L. S. (2002). Hysteria. *Spinal Cord*, 10, 311-312. doi: 10.1038/sj.sc.3101327
- Increasing incidence of rheumatoid arthritis in women. (2008). *Medical News Today*. Retrieved from <http://www.medicalnewstoday.com/articles/126886.php>



- Ironside, P. M., Scheckel, M., Wessels, C., Bailey, M. E., Powers, S., & Seeley, D. K. (2003). Experiencing chronic illness: Cocreating new understandings. *Qualitative Health Research, 13*(2), 171-183. doi: 10.1177/1049732302239597
- Irvine, H., Davidson, C., Hoy, K. and Lowe-Strong, A. (2009). Psychosocial adjustment to multiple sclerosis: Exploration of identity redefinition. *Disability and Rehabilitation, 31*(8), 599-606. doi: 10.1080/09638280802243286
- Jette, A. M., & Keysor, J. J. (2003). Disability models: Implications for arthritis exercise and physical activity interventions. *Arthritis and Rheumatism (Arthritis Care and Research), 49*(1), 114-120. doi: 10.1002/art.10909
- Jones, P. B. B., & Faull, K. (1999). Arthritis: A spiritual journey. *Arthritis Care and Research, 12*(6), 367-368.
- Karp, M. (2010). What has spiritual direction opened for you?. *SDI Membership Moments*. Retrieved from <http://info.sdiworld.org/post/what-has-spiritual-direction-opened-for-you>
- Katz, J. (2002). Ill-health. In N. Thompson (Ed.), *Loss and grief: A guide for human services practitioners* (pp. 149-161). New York, NY: Palgrave.
- Katz, R. C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: A cross validation study that extends the generality of “benefit-finding” in patients with chronic disease. *Journal of Behavioral Medicine, 24*(6), 561-571. doi: 0160-7715/01/1200-0561/0
- Kauffman, J. (1989). Intrapsychic dimensions of disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 25-32). Lexington, MA: Lexington Books.
- Kaye, J., & Raghavan, S. K. (2002). Spirituality in disability and illness. *Journal of Religion and Health, 41*(3), 231-242.
- Kayser, K., & Sormanti, M. (2002). Identity and the illness experience: Issues faced by mothers with cancer. *Illness, Crisis and Loss, 10*(1), 10-26.
- Keck, R. L. (2002). *Healing as a sacred path: A story of personal, medical, and spiritual transformation*. West Chester, PA: Chrysalis Books.
- Keefe, F. J., Affleck, G., Lefebvre, J., Underwood, L., Caldwell, D. S., Drew, J., . . . Pargament, K. I. (2001). Living with rheumatoid arthritis: The role of daily spirituality and daily religious and spiritual coping. *Journal of Pain, 2*(2), 101-110. doi: 10.1054/jpai.2001.19296

- Keefe, F. J., Smith, S., Buffington, A. L. H., Gibson, J., Studts, J. L., & Caldwell, D. S. (2002). Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. *Journal of Consulting and Clinical Psychology, 70*(3), 640-655. doi: 10.1037//0022-006X.70.3.640
- Kelley, J. E., Lumley, M. A., & Leisen, J. C. C. (1997). Health effects of emotional disclosure in rheumatoid arthritis patients. *Health Psychology, 16*(4), 331-340.
- Kelley, P. (1998). Loss experienced in chronic pain and illness. In J. H. Harvey (Ed.), *Perspectives on loss: A sourcebook* (pp. 201-212). Philadelphia, PA: Brunner/Mazel.
- Kinsley, D. (1996). *Health, healing, and religion: A cross-cultural perspective*. Upper Saddle River, NJ: Prentice Hall.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books.
- Kliwer, S. (2004). Allowing spirituality into the healing process. *Journal of Family Practice, 53*(8), 616.
- Koenig, H. G. (2002a). An 83-year-old woman with chronic illness and strong religious beliefs. *JAMA, 288*(4), 487-493. doi: 10.1001/jama.288.4.487
- Koenig, H. G. (2002b). *Spirituality in patient care: Why, how, when, and what*. Philadelphia, PA: Templeton Foundation.
- Koenig, H. G. (2010). Definitions: A thorny issue. In H. G. Koenig (Ed.), *2010 Summer research workshops on spirituality and health* (pp. 52-55). Durham, NC: Center for Spirituality, Theology and Health.
- Koenig, H. G., & Cohen, H. J. (2002a). Psychological stress and autoimmune disease. In H. G. Koenig & H. J. Cohen (Eds.), *The link between religion and health: Psychoneuroimmunology and the faith factor* (pp. 174-196). New York, NY: Oxford University Press.
- Koenig, H. G., & Cohen, H. J. (Eds.). (2002b). *The link between religion and health: Psychoneuroimmunology and the faith factor*. New York, NY: Oxford University Press.
- Koenig, H. G., & McCullough, M. E. (in press). *Handbook of religion and health* (2nd ed.). New York, NY: Oxford University Press.
- Koenig, H. G., McCullough, M. E., & Larson, D. B. (2001). *Handbook of religion and health*. New York, NY: Oxford University Press.

- Kollar, N. R. (1989). Rituals and the disenfranchised griever. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 271-285). Lexington, MA: Lexington Books.
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146-154.
- Kralik, D., Brown, M., & Koch, T. (2001). Women's experiences of "being diagnosed" with a long-term illness. *Journal of Advanced Nursing*, 33(5), 594-602.
- Kreitzer, M. J., Gross, C. R., Waleekhachonloet, O., Reilly-Spong, M., & Byrd, M. (2009). The Brief Serenity Scale: A psychometric analysis of a measure of spirituality and well-Being. *Journal of Holistic Nursing*, 27(1), 7-16. doi: 10.1177/0898010108327212
- Laine, C. (2002). The annual physical examination: Needless ritual or necessary routine? *Annals of Internal Medicine*, 136(9), 701-703.
- Lartey, E. Y. (2003). *In living color: An intercultural approach to pastoral care and counseling* (2nd, revised ed.). London, England: Jessica Kingsley.
- Leas, R. D., & Thomas, J. R. (2008). A brief history of ACPE. Retrieved from ACPE website: <http://www.acpe.edu/cpehistory.htm>
- Leech, K. (2001). *Soul friend: Spiritual direction in the modern world*. Harrisburg, PA: Morehouse.
- Lempp, H., Scott, D., & Kingsley, G. (2006). The personal impact of rheumatoid arthritis on patients' identity: A qualitative study. *Chronic Illness*, 2, 109-120. doi: 10.1177/17423953060020020601
- Levin, J. S. (2001). *God, faith, and health: Exploring the spirituality-healing connection*. Toronto, Canada: John Wiley and Sons Inc.
- Levinson, W., & Lurie, N. (2004). When most doctors are women: What lies ahead? *Annals of Internal Medicine*, 141, 471-474.
- Levy, R. D., & Chan, J. (2006). Spiritual coaching in cancer patients: Treating the spirit as well as the disease. *Journal of Pastoral Care and Counseling*, 60(4), 395-404.
- Liebert, E. (2005). The role of practice in the study of Christian spirituality. In E. A. Dreyer & M. S. Burrows (Eds.), *Minding the spirit: The study of Christian spirituality* (pp. 79-99). Baltimore, MD: The Johns Hopkins University Press.
- Little, B. M. (2007). A ministry of presence: Attending to grief in a season of cheer. *Presence: An International Journal of Spiritual Direction*, 13(4), 41-45.

- Livneh, H. (2001). Psychosocial adaptation to chronic illness and disability: A conceptual framework. *Rehabilitation Counseling Bulletin*, 44(3), 151-160.
- Loffer, S. L. (2000). *Returning to ourselves: Women thriving with chronic illness* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (AAT 9961530)
- Loveys, B. (1990). Transitions in chronic illness: The at-risk role. *Holistic Nursing Practice*, 4(3), 56-64.
- Loyola, I. (trans. 2000). *The spiritual exercises of St. Ignatius* (L. J. Puhl, Trans.). New York, NY: Vintage Books.
- Luckhaupt, S. E., Yi, M. S., Mueller, C. V., Mrus, J. M., Peterman, A. H., Puchalski, C. M., & Tsevat, J. (2005). Beliefs of primary care residents regarding spirituality and religion in clinical encounters with patients: A study at a midwestern U.S. teaching institution. *Academic Medicine*, 80(6), 560-570.
- Lundman, B., & Jansson, L. (2007). The meaning of living with a long-term disease. To revalue and be revalued. *Journal of Nursing and Healthcare of Chronic Illness*, 16(7b), 109-115. doi: 10.1111/j.1365-2702.2006.01802.x
- Lupus: Frequently asked questions. (2010). Retrieved from <http://www.womenshealth.gov/faq/lupus.cfm#3>
- Lyons, R. F., & Sullivan, M. J. L. (1998). Curbing loss in illness and disability: A relationship perspective. In J. H. Harvey (Ed.), *Perspectives on loss: A sourcebook* (pp. 137-152). Philadelphia, PA: Brunner/Mazel.
- MacLean, C. D., Susi, B., Phifer, N., Schultz, L., Bynum, D., Franco, M., . . . Cykert, S. (2003). Patient preference for physician discussion and practice of spirituality. *Journal of General Internal Medicine*, 18, 38-43.
- Maggio, L. M. (2007). Externalizing lupus: A therapist's/patient's challenge. *Professional Psychology: Research and Practice*, 38(6), 576-581. doi: 10.1037/0735-7028.38.6.576
- Magid, C. S. (2000). Pain, suffering, and meaning. *JAMA*, 283(1), 114. doi: 10.1001/jama.283.1.114-a
- Mairs, N. (1989). *Remembering the bonehouse: An erotics of place and space*. New York, NY: Harper and Row.
- Mann, S. B. (1982). *Being ill: Personal and social meaning*. New York, NY: Irvington Publishers.

- Margaretten, M., Yelin, E., Imboden, J., Graf, J., Barton, J., Katz, P., & Julian, L. (2009). Predictors of depression in a multiethnic cohort of patients with rheumatoid arthritis. *Arthritis and Rheumatism*, *61*(11), 1586-1591. doi: 10.1002/art.24822
- Marshall, J. L. (2004). Methods in pastoral theology, care, and counseling. In N. J. Ramsay (Ed.), *Pastoral care and counseling: Redefining the paradigms* (pp. 133-154). Nashville: Abingdon.
- Matsumoto, A. K. (2010). Rheumatoid arthritis clinical presentation. *Johns Hopkins Arthritis Center*. Retrieved from [http://www.hopkins-arthritis.org/arthritis-info/rheumatoid-arthritis/rheum\\_clin\\_pres.html](http://www.hopkins-arthritis.org/arthritis-info/rheumatoid-arthritis/rheum_clin_pres.html)
- McCauley, J., Tarpley, M. J., Haaz, S., & Bartlett, S. J. (2008). Daily spiritual experiences of older adults with and without arthritis and the relationship to health outcomes. *Arthritis and Rheumatism (Arthritis Care and Research)*, *59*(1), 122-128. doi: 10.1002/art.23246
- McConnell, K. M., & Pargament, K. I. (2006). Examining the links between spiritual struggles and symptoms of psychopathology in a national sample. *Journal of Clinical Psychology*, *62*(12), 1469-1484. doi: 10.1002/jclp.20325
- McIntosh, D. N. (1997). Religion-as-schema, with implications for the relation between religion and coping. In B. Spilka & D. N. McIntosh (Eds.), *The psychology of religion: Theoretical approaches* (pp. 171-183). Boulder, CO: Westview Press.
- McNulty, K. (2007). Coping with multiple sclerosis: Considerations and interventions. In E. Martz & H. Livneh (Eds.), *Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects* (pp. 289-312). New York, NY: Springer.
- McNulty, K., Livneh, H., & Wilson, L. M. (2004). Perceived uncertainty, spiritual well-being, and psychosocial adaptation in individuals with multiple sclerosis. *Rehabilitation Psychology*, *49*(2), 91-99. doi: 10.1037/0090-5550.49.2.91
- McPherson, R. H. (1980). The chronic pain patient: The role of the pastor as helper. *Christian Ministry*, *11*, 24-26.
- McSherry, W., & Cash, K. (2004). The language of spirituality: An emerging taxonomy. *International Journal of Nursing Studies*, *41*(2), 151-161. doi: 10.1016/S0020-7489(03)00114-7
- Meagher, D. K. (1989). The counselor and the disenfranchised griever. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 313-328). Lexington, MA: Lexington Books.

- Mehl-Madrona, L. E. (2003). *Coyote healing: Miracles in native medicine*. Rochester, VT: Bear and Company.
- Melzack, R. (1975). The McGill Pain Questionnaire: Major properties and scoring methods. *Pain, 1*, 277-299.
- Miles, A. (2009). Of butterflies and wolves: enacting lupus transformations on the Internet. *Anthropology and Medicine, 16*(1), 1-12. doi: 10.1080/13648470802425906
- Miller-McLemore, B. J. (1996). The living human web: Pastoral theology at the turn of the century. In J. S. Moessner (Ed.), *Through the eyes of women: Insights for pastoral care* (pp. 9-26). Minneapolis, MN: Fortress Press
- Miller-McLemore, B. J. (2004). Pastoral theology as public theology: Revolutions in the 'Fourth Area'. In N. J. Ramsay (Ed.), *Pastoral care and counseling: Redefining the paradigms* (pp. 45-64). Nashville, TN: Abingdon.
- Miller-McLemore, B. J. (2010). Cognitive neuroscience and the question of theological method. *Journal of Pastoral Theology, 20*(2), 64-92.
- Mitchell, K. R., & Anderson, H. (1983). *All our losses, all our griefs: Resources for pastoral care*. Louisville, KY: Westminster John Knox Press.
- Mohr, D. C., Dick, L. P., Russo, D., Pinn, J., Boudewyn, A. C., Likosky, W., & Goodkin, D. E. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology, 18*(4), 376-382.
- Montgomery, G. A. (2003). *Grief needs a witness: A psychological study of the witness, from the perspective of Jungian psychology and self psychology* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (AAT 3128808)
- Moses, N., Wiggers, J., & Nicholas, C. (2008). Persistence of unmet need for care among people with systemic lupus erythematosus: A longitudinal study. *Quality of Life Research, 17*, 867-876. doi: 10.1007/s11136-008-9361-2
- Muldoon, M. H., & King, N. J. (1991). A spirituality for the long haul: Response to chronic illness. *Journal of Religion and Health, 30*, 99-108.
- Nakazawa, D. J. (2010). *The autoimmune epidemic: Bodies gone haywire in a world out of balance and the cutting-edge science that promises hope*. New York, NY: Touchstone.

- Nayak, S., Matheis, R. J., Schoenberger, N. E., & Shiflett, S. C. (2002). Use of unconventional therapies by individuals with multiple sclerosis. *Clinical Rehabilitation, 17*(2), 181-191. doi: 10.1191/0269215503cr604oa
- Neimeyer, R. A. (2001a). Introduction: Meaning reconstruction and loss. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 1-9). Washington, DC: American Psychological Association.
- Neimeyer, R. A. (2001b). The language of loss: Grief therapy as a process of meaning reconstruction. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 261-292). Washington, DC: American Psychological Association.
- Neimeyer, R. A., & Keesee, N. J. (1998). Dimensions in diversity in the reconstruction of meaning. In K. J. Doka & J. D. Davidson (Eds.), *Living with grief: Who we are, how we grieve* (pp. 223-237). Washington, DC: Hospice Foundation of America.
- Nelson, S. (2003). Facing evil: Evil's many faces. Five paradigms for understanding evil. *Interpretation, 57*(4), 398-413.
- Neuger, C. C. (2001). *Counseling women: A narrative, pastoral approach*. Minneapolis, MN: Fortress Press.
- O'Connell, K. A., & Skevington, S. M. (2007). To measure or not to measure? Reviewing the assessment of spirituality and religion in health-related quality of life. *Chronic Illness, 3*(1), 77-87. doi: 10.1177/1742395307079195
- O'Neill, E. S., & Morrow, L. L. (2001). The symptom experience of women with chronic illness. *Journal of Advanced Nursing, 33*(2), 257-268.
- Pakenham, K. I. (2008). Making sense of illness or disability: The nature of sense making in multiple sclerosis (MS). *Journal of Health Psychology, 13*(1), 93-105. doi: 10.1177/1359105307084315
- Pakenham, K. I., & Cox, S. (2009). The dimensional structure of benefit finding in multiple sclerosis and relations with positive and negative adjustment: A longitudinal study. *Psychology and Health, 24*(4), 373-393. doi: 10.1080/08870440701832592
- Pargament, K. I. (1997). *The psychology of religion and coping: Theory, research, practice*. New York, NY: Guilford Press.
- Pargament, K. I. (2007). *Spiritually-integrated psychotherapy: Understanding and addressing the sacred*. New York, NY: Guilford Press.

- Pargament, K. I., Ano, G. G., & Wachholtz, A. B. (2005). The religious dimension of coping: Advances in theory, research, and practice. In R. F. Paloutzian & C. L. Park (Eds.), *Handbook of the psychology of religion and spirituality* (pp. 479-495). New York, NY: The Guilford Press.
- Pargament, K. I., & Hahn, J. (1986). God and the just world: Causal and coping attributions to God in health situations. *Journal for the Scientific Study of Religion*, 25(2), 193-207.
- Pargament, K. I., Koenig, H. G., & Perez, L. M. (2000). The many methods of religious coping: Development and initial validation of the RCOPE. *Journal of Clinical Psychology*, 56(4), 519-543.
- Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology*, 9(6), 713-730. doi: 10.1177/1359105304045366
- Pargament, K. I., Murray-Swank, N. A., Magyar, G. M., & Ano, G. G. (2005). Spiritual struggle: A phenomenon of interest to psychology and religion. In W. R. Miller & H. D. Delaney (Eds.), *Judeo-Christian perspectives on psychology* (pp. 245-268). Washington, DC: American Psychological Association.
- Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. M. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion*, 37(4), 710-724.
- Park, C. L. (2007). Religiousness/spirituality and health: A meaning systems perspective. *Journal of Behavioral Medicine*, 30, 319-328. doi: 10.1007/s10865-007-9111-x
- Parrish, B. P., Zautra, A. J., & Davis, M. C. (2008). The role of positive and negative interpersonal events on daily fatigue in women with fibromyalgia, rheumatoid arthritis, and osteoarthritis. *Health Psychology*, 27(6), 694-702. doi: 10.1037/0278-6133.27.6.694
- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33(1), 21-26.
- Pattison, S. (1989). *Alive and kicking: Towards a practical theology of illness and healing*. London, England: SCM Press Ltd.
- Patton, J. (1993). *Pastoral care in context: An introduction to pastoral care*. Louisville, KY: Westminster/John Knox Press.



- Pembroke, N. F. (2008). Appropriate spiritual care by physicians: A theological perspective. *Journal of Religion and Health, 47*, 549–559. doi: 10.1007/s10943-008-9183-0
- Pennebaker, J. W. (1997). *Opening up: The healing power of expressing emotions* (2nd ed.). New York, NY: Guilford Press.
- Pesek, E. M. (2002). The role of support groups in disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 127-133). Champaign, IL: Research Press.
- Peterman, A. H., Fitchett, G., Brady, J. M., Hernandez, L., & Cella, D. (2002). Measuring spiritual well-being in people with cancer: The Functional Assessment of Chronic Illness Therapy--Spiritual well-being scale (FACIT-Sp). *Annals of Behavioral Medicine, 24*(1), 49-58.
- Pettersson, S., Möller, S., Svenungsson, E., Gunnarsson, I., & Henriksson, E. W. (2010). Women's experience of SLE-related fatigue: A focus group interview study. *Rheumatology, 49*(10), 1935-1942. doi: 10.1093/rheumatology/keq174
- Philip, E. J., Lindner, H., & Lederman, L. (2009). Relationship of illness perceptions with depression among individuals diagnosed with lupus. *Depression and Anxiety, 26*, 575-582. doi: 10.1002/da.20451
- Phillips, R. E., Pargament, K. I., Lynn, Q. K., & Crossley, C. D. (2004). Self-directing religious coping: A deistic God, abandoning God, or no God at all? *Journal for the Scientific Study of Religion, 43*, 409-418.
- Plach, S. K., Stevens, P. E., & Moss, V. A. (2004a). Corporeality: Women's experiences of a body with rheumatoid arthritis. *Clinical Nursing Research, 13*(2), 137-155. doi: 10.1177/1054773803262219
- Plach, S. K., Stevens, P. E., & Moss, V. A. (2004b). Social role experiences of women living with rheumatoid arthritis. *Journal of Family Nursing, 10*, 33-49. doi: 10.1177/1074840703261065
- Porter, R. (Ed.). (1997). *Medicine: A history of healing: Ancient traditions to modern practice*. Thailand: The Ivy Press Limited.
- Prognosis and a hopeful future. (2010). Retrieved from [http://www.lupus.org/webmodules/webarticlesnet/templates/new\\_learnunderstanding.aspx?articleid=2238&zoneid=523](http://www.lupus.org/webmodules/webarticlesnet/templates/new_learnunderstanding.aspx?articleid=2238&zoneid=523)
- Puchalski, C. M. (2006a). Spirituality and medicine: Curricula in medical education. *Journal of Cancer Education, 21*(1), 14-18. doi: 10.1207/s15430154jce2101\_6

- Puchalski, C. M. (2006b). *A time for listening and caring: Spirituality and the care of the chronically ill and dying*. New York, NY: Oxford University Press.
- Puchalski, C. M., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., . . . Sulmasy, D. P. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine*, *12*(10), 885-904. doi: 10.1089=jpm.2009.0142
- Ramsay, N. J. (2004). A time of ferment and redefinition. In N. J. Ramsay (Ed.), *Pastoral care and counseling: Redefining the paradigms* (pp. 1-43). Nashville, TN: Abingdon.
- Reeves, N. (2007). Grief and spirituality. *Presence: An International Journal of Spiritual Direction*, *13*(4), 34-40.
- Reynolds, F., & Prior, S. (2003). "Sticking jewels in your life": Exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research*, *13*(9), 1225-1251. doi: 10.1177/1049732303257108
- Roter, D. L., & Hall, J. A. (2004). Physician gender and patient-centered communication: A critical review of empirical research. *Annual Review of Public Health*, *25*, 497-519. doi: 10.1146/annurev.pubhealth.25.101802.123.134
- Rowe, M. M., & Allen, R. G. (2004). Spirituality as a means of coping with chronic illness. *American Journal of Health Studies*, *19*(1), 62-67.
- Ruffing, J. K. (2000). *Spiritual direction: Beyond the beginnings*. New York, NY: Paulist Press.
- Ruffing, J. K. (2006). Spiritual direction with women: Reclaiming and reinterpreting key themes from the spiritual tradition. *Presence: An International Journal of Spiritual Direction*, *12*(3), 36-46.
- Russell, C. S., White, M. B., & White, C. P. (2006). Why me? Why now? Why multiple sclerosis?: Making meaning and perceived quality of life in a Midwestern sample of patients with multiple sclerosis. *Families, Systems, and Health*, *24*(1), 65-81. doi: 10.1037/1091-7527.24.1.65
- Sapey, B. (2004). Impairment, disability, and loss: Reassessing the rejection of loss. *Illness, Crisis and Loss*, *12*(1), 90-101.
- Schneiders, S. M. (2005a). A hermeneutical approach to the study of Christian spirituality. In E. A. Dreyer & M. S. Burrows (Eds.), *Minding the spirit: The study of Christian spirituality* (pp. 49-60). Baltimore, MD: The Johns Hopkins University Press.

- Schneiders, S. M. (2005b). The study of Christian spirituality: Contours and dynamics of a discipline. In E. A. Dreyer & M. S. Burrows (Eds.), *Minding the spirit: The study of Christian spirituality* (pp. 5-24). Baltimore, MD: The Johns Hopkins University Press.
- Seawell, A. H., & Danoff-Burg, S. (2005). Body image and sexuality in women with and without systemic lupus erythematosus. *Sex Roles, 53*(11/12), 865-876. doi: 10.1007/s11199-005-8298-y
- Sered, S. S. (1992). *Women as ritual experts: The religious lives of elderly Jewish women in Jerusalem*. New York, NY: Oxford University Press.
- Sidell, N. (1997). Adult adjustment to chronic illness: A review of the literature. *Health and Social Work, 22*(1), 5-11.
- Sloan, R. P., Bagiella, E., & Powell, T. (1999). Religion, spirituality, and medicine. *The Lancet, 353*, 664-667.
- Smart, J. F., & Smart, D. W. (2006). Models of disability: Implications for the counseling profession. *Journal of Counseling and Development, 84*, 29-40.
- Smith, J. Z. (1980). The bare facts of ritual. *History of Religions, 19*(4), 112-127.
- Spencer-Benson, F. M. (2003). *The power within illness: Uncovering the essence of transformation through the experience of illness* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (AAT NQ85204)
- Sperry, L., & Shafranske, E. P. (2005). *Spiritually oriented psychotherapy*. Washington, DC: American Psychological Association.
- Sprangers, M. A. G., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science and Medicine, 48*, 1507-1515.
- Stamm, T., Lovelock, L., Stew, G., Nell, V., Smolen, J., Jonsson, H., . . . Machold, K. (2008). I have mastered the challenge of living with a chronic disease: Life stories of people with rheumaoid arthritis. *Qualitative Health Research, 18*(5), 658-669. doi: 10.1177/1049732308316348
- Steck, B., Amsler, F., Kappos, L., & Bürgin, D. (2000). Gender-specific differences coping with chronic somatic disease (e.g., multiple sclerosis). *Archives of Women's Mental Health, 3*, 15-21.
- Sterba, K. R., DeVellis, R. F., Lewis, M. A., DeVellis, B. M., Jordan, J. M., & Baucom, D. H. (2008). Effect of couple illness perception congruence on psychological

- adjustment in women with rheumatoid arthritis. *Health Psychology, 27*(2), 221-229. doi: 10.1037/0278-6133.27.2.221
- Strunk, O. C. (2004). Needed: A phenomenology of illness. *Journal of Pastoral Care and Counseling, 58*(4), 293-294.
- Stuifbergen, A. K., & Harrison, T. C. (2003). Complementary and alternative therapy use in persons with multiple sclerosis. *Rehabilitation Nursing, 28*(5), 141-158.
- Sullender, R. S. (1979). Three theoretical approaches to grief. *Journal of Pastoral Care, 33*(4), 243-251.
- Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability and Society, 15*(4), 569-582. doi: 10.1080/09687590050058189
- Swinton, J. (2007). *Raging with compassion: Pastoral responses to the problem of evil*. Grand Rapids, MI: William B. Eerdmans Publishing.
- Taïeb, O., Bricou, O., Baubet, T., Gaboulaud, V., Gal, B., Mouthon, L., . . . Moro, M. R. (2010). Patients' beliefs about the causes of systemic lupus erythematosus. *Rheumatology, 49*(3), 592-599. doi: 10.1093/rheumatology/kep430
- Tang, S. Y. S., & Anderson, J. M. (1999). Human agency and the process of healing: Lessons learned from women living with a chronic illness—"rewriting the expert". *Nursing Inquiry, 6*, 83-93.
- Tanyi, R. A. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing, 39*(5), 500-509.
- Taylor, S. (2007). What to expect in Buddhist spiritual direction. *Presence: An International Journal of Spiritual Direction, 13*(3), 46-52.
- Thernstrom, M. (2010). *The pain chronicles: Cures, myths, mysteries, prayers, diaries, brain scans, healing, and the science of suffering*. New York, NY: Farrar, Straus, and Giroux.
- Thompson, N. (2002). Introduction. In N. Thompson (Ed.), *Loss and grief: A guide for human services practitioners* (pp. 1-20). New York, NY: Palgrave.
- Thorne, S., McCormick, J., & Carty, E. (1997). Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International, 18*(1), 1-16. doi: 10.1080/07399339709516255
- Thorne, S., & Paterson, B. (1998). Shifting images of chronic illness. *Image: Journal of Nursing Scholarship, 30*(2), 173-178.

- Townsend, L. (2009). *Introduction to pastoral counseling*. Nashville, TN: Abingdon.
- Townsend, M., Kladder, V., & Mulligan, T. (2002). Systematic review of clinical trials examining the effects of religion and health. *Southern Medical Journal*, *95*(12), 1429-1434.
- Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, C. A., & Tsevat, J. (2010). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS Behavior*, *14*, 379-389. doi: 10.1007/s10461-007-9332-6
- Underhill, E. (2005/1930). *Mysticism: A study in the nature and development of spiritual consciousness*. Stillwell, KS: Digireads.com Publishing.
- Underwood, R. L. (2006). Enlarging hope for wholeness: Ministry with persons in pain. *Journal of Pastoral Care and Counseling*, *60*(1-2), 3-12.
- Uramoto, K. M. (1999). Trends in the incidence and mortality of sytemic lupus erythematosus, 1950-1992. *Arthritis and Rheumatism*, *42*(1), 46-50. doi: 10.1002/1529-0131(199901)
- Vandecreek, L., Paget, S., Horton, R., Robbins, L., Oettinger, M., & Tai, K. (2004). Religious and nonreligious coping methods among persons with rheumatoid arthritis. *Arthritis and Rheumatism (Arthritis Care and Research)*, *51*(1), 49-55. doi: 10.1002/art.20074
- Vander Zee, J. (2002). The chronically ill patient. In R. B. Gilbert (Ed.), *Health care and spirituality: Listening, assessing, caring* (pp. 179-187). Amityville, NY: Baywood Publishing.
- Verghese, A. (2011). Treat the patient, not the CT scan. *New York Times*. Retrieved from <http://www.nytimes.com/2011/02/27/opinion/27verghese.html?scp=1&sq=treat%20the%20patient,%20not%20the%20ct%20scan&st=cse>
- Vest, N. (2000). *Still listening: New horizons in spiritual direction*. Harrisburg, PA: Morehouse.
- Vest, N. (2003). *Tending the holy: Spiritual direction across traditions*. Harrisburg, PA: Morehouse.
- Vickers, M. H. (2000). Stigma, work, and "unseen" illness: A case and notes to enhance understanding. *Illness, Crisis and Loss*, *8*(2), 131-151.
- The vision of Spiritual Directors International. (2011). Retrieved from sdiworld.org website: <http://sdiworld.org/index.pl/mission.html>

- Wachholtz, A. B., & Pargament, K. I. (2008). Migraines and meditation: Does spirituality matter? *Journal of Behavioral Medicine, 31*, 351-366. doi: 10.1007/s10865-008-9159-2
- Waddell, H. (1998). *The desert fathers*. New York, NY: Vintage Books.
- Wagner, N. (Ed.). (2006). *Spiritual direction in context*. Harrisburg, PA: Morehouse.
- Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment to chronic illness: Using the example of rheumatoid arthritis. *Clinical Psychology Review, 24*(4), 461-488. doi: 10.1016/j.cpr.2004.03.001
- Warren, R. C. (2007). The impact of horizontal and vertical dimensions of faith on health and health care. *Journal of the Interdenominational Theological Center, 34*(1-2), 71-85.
- Wasan, A. D., Wootton, J., & Jamison, R. N. (2005). Dealing with difficult patients in your pain practice. *Regional Anesthesia and Pain Medicine, 30*(2), 184-192. doi: 10.1016/j.rapm.2004.11.005
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.
- What is complementary and alternative medicine? (2010). Retrieved from National Center for Complementary and Alternative Medicine website: <http://nccam.nih.gov/health/whatiscam/>
- What is rheumatoid arthritis? (2010). Retrieved from Arthritis Foundation <http://www.arthritis.org/types-what-is-rheumatoid-arthritis.php>
- What is the difference between a Stephen Ministry relationship and a friendship? (2011). Retrieved from <http://www.stephenministries.org/stephenministry/default.cfm/1225>
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York, NY: W. W. Norton & Company.
- Whittemore, R., & Dixon, J. (2008). Chronic illness: The process of integration. *Journal of Clinical Nursing, 17*(7b), 177-187. doi: 10.1111/j.1365-2702.2007.02244.x
- Who gets rheumatoid arthritis? (2007). Retrieved from Arthritis Foundation <http://www.arthritis.org/who-gets-rheumatoid-arthritis.php>
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness, 6*(2), 175-200.

- Williams, J., & Koocher, G. P. (1998). Addressing loss of control in chronic illness: Theory and practice. *Psychotherapy* 35(3), 325-335.
- Wong-McDonald, A., & Gorsuch, R. (2000). Surrender to God: An additional coping style? *Journal of Psychology and Theology*, 28(2), 149-161.
- Worth, H., Reid, A., & McMillan, K. (2002). Somewhere over the rainbow: Love, trust and monogamy in gay relationships. *Journal of Sociology* 38(3), 237–253. doi: 10.1177/144078302128756642
- Yanez, B., Edmondson, D., Stanton, A. L., Park, C. L., Kwan, L., Ganz, P. A., & Blank, T. O. (2009). Facets of spirituality as predictors of adjustment to cancer: Relative contributions of having faith and finding meaning. *Journal of Consulting and Clinical Psychology*, 77(4), 730-741. doi: 10.1037/a0015820
- Young, L. D. (1992). Psychological factors in rheumatoid arthritis. *Journal of Consulting and Clinical Psychology*, 60(4), 619-627.
- Zinnbauer, B. J., Pargament, K. I., Cole, B. S., Rye, M. S., Butter, E. M., Belavich, T. G., . . . Kadar, J. L. (1997). Religion and spirituality: Unfuzzifying the fuzzy. *Journal for the Scientific Study of Religion*, 36(4), 549-564.

## Appendix

### Approaches to Spiritual and Pastoral Care

	Spiritual direction	Pastoral counseling	Pastoral/chaplaincy care
<b>Contract of care</b>	Long-term: may last for years	Short-term: average 8 weeks	Short-term: typically 1-6 visits
<b>Initiated by</b>	Careseeker desire for spiritual growth, deeper relationship with God/the transcendent, discernment	Careseeker desire for problem resolution (e.g., trauma, emotional or spiritual distress, addiction, depression, relationship issues)	Caregiver response to major life event (e.g., health crisis, impending death, loss, violence); may include supportive follow-up care  or Careseeker desire for problem resolution (e.g., spiritual or emotional distress, relationship issues)
<b>Primary goals</b>	Awareness of presence/activity of God/the transcendent in the careseeker's life  Discernment of and response to call or purpose  Spiritually-contextual meaning making  Spiritual formation (e.g., develop gifts and virtues, enhance coping strategies and spiritual practices)  Mind-body-spirit integration	Careseeker safety  Resolution of presenting problem  Effective coping and adjustment  Meaning making  Self-understanding/acceptance  Spiritual guidance	Careseeker safety  Presence of God/the transcendent with the careseeker in suffering  Lament losses  Effective coping  Meaning making  Spiritual guidance
<b>Context of care</b>	Locations vary widely (e.g., home, faith community venue, outdoors)  Established duration/frequency; typically 1 hour/month; may be as infrequent as one session/year  Caregiver may or may not be associated with a particular faith community; caregiver and careseeker faith traditions vary widely  One-on-one and group care (with other careseekers), depending on careseeker preference  Refer as needed to other caregivers	Professional counseling office or faith community venue  Established duration/frequency; typically 1 hour/week for 8 weeks  Caregivers and careseekers typically of same faith tradition  One-on-one care; may occasionally include other members of careseeker's support community  Refer as needed to other caregivers	Locations vary widely (e.g., faith community venue, hospital, accident scene, careseeker's home)  Times vary widely depending on degree of planning and formality of visit (e.g., care may occur in a hallway conversation); visits often brief  Caregivers typically associated with a faith tradition, chaplains may be of different faith tradition than careseeker  One-on-one care; frequently includes other members of careseeker's support community  Refer as needed to other caregivers
<b>Care relationship</b>	Clergy or lay spiritual director  Collaborative  Contemplative and intuitive approach  Hermeneutic of trust/not-knowing	Pastoral counselor; may also be clergy  Collaborative and/or directive  Analytical approach  Hermeneutic of suspicion	Clergy or lay caregiver  Collaborative and/or directive  Non-anxious caring presence  Trust relationship