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The Process of Identity Management in Individuals Living with Systemic Scleroderma

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THE PROCESS OF IDENTITY MANAGEMENT IN INDIVIDUALS LIVING WITH SYSTEMIC SCLERODERMA

by

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ABSTRACT

THE PROCESS OF IDENTITY MANAGEMENT IN INDIVIDUALS LIVING WITH SYSTEMIC SCLERODERMA

by

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Under the Supervision of Professor Jennifer Doering, PhD, RN

Background: Individuals with chronic illnesses may struggle to adapt psychologically to the illness experience and have feelings of identity loss, self-diminishment, and biographical disruption. This, in turn, may limit an individual's ability to engage in optimal self-management. Systemic scleroderma is a debilitating, stigmatizing, and life-limiting progressive chronic illness with significant disfiguring effects. Little is known about the identity management process in individuals with scleroderma. The purpose of this study was to generate a grounded theory of the identity management process in people with systemic scleroderma.

Methods: Grounded theory methodology was used to uncover the basic social process of identity management in individuals living with systemic scleroderma. Fifteen women with systemic scleroderma were recruited using theoretical sampling to ensure representation of differing illness duration and progression. Semi-structured interviews were conducted in person or by phone, transcribed, and analyzed using open, selective, and theoretical coding. Rigor was assured through multiple procedures.

Results: Four core categories emerged. *Adapting to Changes* are the behaviors that participants struggled through to carry on with their everyday lives. *Dismantling of Self* was an internal process where participants lost their sense of self and purpose. *Reclaiming Self* was the basic social process that involved a deep internal process to include letting go, reevaluating who they

were inside, and realizing that who they were had never changed. *Embracing Self* was a transformative process that allowed participants to rewrite and rebuild their biographies and to live with renewed purpose, intention, gratefulness, and appreciation of their contributions to others.

Discussion: Findings suggest that the management of identity was important for understanding how individuals adapt to life with systemic scleroderma. This study can help nurses better understand how to support patients holistically with management of systemic scleroderma.

To everyone living with scleroderma.

You taught me what it means to “come home again.”

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Chapter I: Introduction

Chronic disease is the leading cause of death and disability in the United States. Approximately half of all adults (117 million people) have one or more chronic conditions and one in four adults have two or more chronic conditions (Centers for Disease Control and Prevention [CDC], 2016a). Seven out of 10 deaths annually are due to a chronic disease, with 86% of our national healthcare costs going to treat individuals with a chronic illness (CDC, 2016a). Chronic illness can present a challenge for role identification (Oksel & Gunduzoglu, 2014). Once someone is diagnosed with a chronic illness, individual and social roles quite possibly change, as well. Roles help to develop personal identity and having a chronic illness can challenge the meaning of these roles (Chaboyer, Lee, Wallis, Gillespie, & Jones, 2010; Dickson, Knussen, & Flowers, 2008; Harman & Clare, 2006; Kralik, Brown, & Koch, 2001; Mendelson, 2006; Oksel & Gunduzoglu, 2014; Thornhill, Lyons, Nouwen, & Lip, 2008). How individuals create an understanding of their chronic illness is important, because this understanding can impact the management of that illness.

Identity is personal and can be represented both internally and externally. Illness perceptions tend to contain identity elements (Larsen, 2013). When a chronic illness compromises one's identity, a person may struggle with holding onto their identity when aspects of this identity are diminished due to chronic illness. This feeling of self-diminishment manifests as physical and psychological changes take place because of living with a chronic illness. The primary seminal work related to the concept of *loss of self* began with Kathy Charmaz (1983, 1995), when she posited that loss of self and loss of identity were interchangeable. Subsequent studies have also supported this claim (Cowan, Bommersbach, & Curtis, 1995; Nochi, 1998; Skaff & Pearlin, 1992). Self-concept and self-image contribute to individual understanding of

self and identity. Life events tend to precede this sense of loss of self. Illness and suffering, along with anxiety, anger, and guilt, contribute and coexist with a person's sense of loss of self.

As individuals continue to live and suffer with a chronic illness, their sense of self-control, self-esteem, and, ultimately, self-identity may become eroded (Charmaz, 1983; Singh, Clements, Furst, Maranian, & Khanna, 2012). Consistency and predictability reinforce one's identity. When identity is challenged, as with an onset or diagnosis of a chronic illness, there is a loss of something that made up the wholeness of who that person once saw themselves as being (Charmaz, 1983). As individuals attempt to live with their chronic illness, they begin to reorganize their life schema.

Systemic scleroderma is a debilitating and life-limiting progressive chronic illness with disfiguring effects and is costly to manage. Exploring identity management in individuals with systemic scleroderma is an ideal way to study the identity management process, because scleroderma is disfiguring, stigmatizing, and challenging to an individual's coping or adaptation psychologically (Cinar et al., 2013; Gumuchian et al., 2016; Joachim & Acorn, 2003; Oksel & Gunduzoglu, 2014).The work accomplished by Ryan and Sawin (2009) has informed the initial effort of this study.

The individual and family self-management theory (IFSMT) by Ryan and Sawin (2009) is a mid-range descriptive theory proposing that individuals and families assume the responsibility for managing the health outcomes of their acute and chronic conditions. Three dimensions are instrumental in the IFSMT: context, process, and outcome. Behavioral change is a significant component under the process dimension. Within the process dimension, physical, emotional, and cognitive responses are influential in achieving behavioral changes that lead to self-management. An assumption is that in order for these changes to take place, an individual

must believe in self-efficacy, or the internal belief that they can accomplish or succeed at a behavior change. An individual's sense of identity may be a powerful factor under the process dimension. A sense of loss associated with a chronic condition may affect the dimension process within the IFSMT. The concept of identity should be taken into consideration when discussing self-management and may help with developing resilience in a chronic illness.

Statement of the Problem

Systemic scleroderma is an incurable, rare, autoimmune connective tissue disease. Most studies related to scleroderma and systemic scleroderma focus heavily on the medical and molecular perspective, with the purpose of trying to find a cure or, at best, lessen the symptoms. Nurses typically have little knowledge about scleroderma, which makes it difficult for nurses to understand how this chronic disease impacts individuals living with scleroderma, especially systemic scleroderma. In a study by Joachim and Acorn (2003), participants expressed this concern and stated that they wished nurses understood scleroderma better and how it impacts them physically and psychologically.

Appearance is a major concern for individuals living with scleroderma. In addition to appearance, studies have also looked at other concepts, such as quality of life, stigma, depression, anxiety, fear, loss, uncertainty, and diminishment of roles (Benrud-Larson et al., 2003; Gumuchian et al., 2016; Heinberg et al., 2007; Joachim & Acorn, 2003; Oksel & Gunduzoglu, 2014). When these concepts are synthesized together, they all contribute to one's sense of self, or what is otherwise known as identity. Nurses are concerned about helping patients self-manage their chronic conditions; however, nurses may overlook the psychological impact to a patient with a chronic condition such as scleroderma, which is a relatively rare condition not often seen by nurses. Understanding the human condition related to scleroderma is

important, with a need to investigate how the process of identity is managed for individuals living with systemic scleroderma. By learning about identity in individuals with scleroderma, we may learn also about identity changes in chronic illness and, thus, advance the science.

Purpose Statement and Research Questions

The purpose of this study was to explore the process of identity management in people living with systemic scleroderma. The questions driving this research are:

Research Question 1: How does identity of people with systemic scleroderma change over time?

Research Question 2: How does the onset and progression of systemic scleroderma affect roles and self-concept?

Significance of the Study

The phenomenon of identity management in individuals living with systemic scleroderma is the focus of this dissertation. Having a better understanding of how individuals experience and process the identity elements relating to a chronic and progressive illness, such as systemic scleroderma, will advance nursing science, because this knowledge will fill a gap that may improve how nurses leverage identity changes in patients living with systemic scleroderma. Potentially, this study may also optimize the management of other chronic illnesses where one's identity is challenged or diminished. Finally, the findings of this study may help with creating nursing interventions to assist with identity management of individuals living with a chronic condition.

Assumptions

There are several assumptions at the forefront of this study:

1) Living with a chronic illness obliges one to make changes in his or her life (Ambrosio et al., 2015; Clarke & Bennett, 2013; Joesey, 2016; Lundman & Jansson, 2007).
2) Identity development is instrumental to a person's sense of purpose, self-concept, and sense of authenticity (Joachim & Acorn, 2003; Karnilowicz, 2001; Vallido, Wilkes, Carter, & Jackson, 2010).
3) Living with a rapidly disfiguring chronic illness can affect one's sense of self, creating an experience of loss of self (Joachim & Acorn, 2003; Oksel & Gunduzoglu, 2014).
4) Even in a disfiguring chronic illness, such as systemic scleroderma, there are moments of positive self-growth that can redefine a sense of purpose (Lebel et al., 2013; Purc-Stephenson, Bowlby, & Qaqish, 2015).

Definition of Terms

Chronic illness: "The personal experience of living with the affliction that often accompanies a chronic disease" (Martin, 2007, p. 2086).

Loss of self: "A fundamental form of suffering where one's former self-images fall away without the simultaneous development of equally valued new ones" (Charmaz, 1983, p. 168).

Identity: The "properties of sameness and distinction that link the interior world of psychological experience and the exterior world of language and categorization" (Hammack, 2015, p. 12). Identity is a sense of internal coherence and continuity (Hammack, 2015).

Self-concept: Our "perception or image of our abilities and our uniqueness" (Pastorino & Doyle-Portillo, 2016, p. 486).

Stigma: "Discrediting another based upon widely held social beliefs about personality, behavior, and illness, and is communicated to individuals through a process of socialization" (Stuenkel & Wong, 2013, p. 50).

Summary

Identity management can be a challenge for someone living with systemic scleroderma. How individuals make sense of and create an understanding of what their chronic illness (systemic scleroderma) means personally to them is also important. Identity creates a sense of self-worth and purpose, where one belongs in the large picture. This sense of self-worth comes attached to roles and social expectations. Self-concept and self-image also contribute to an individual's sense of self and identity. Living with a chronic illness may include a sense of loss, losing something that once was, but can no longer be salvaged. This loss of self is significant in people living with systemic scleroderma. Understanding what the social process is for identity management in individuals living with systemic scleroderma is important for nurses. By understanding what this basic social process is, nurses will be able to better care for individuals living with scleroderma, and most importantly, nurses will be able to incorporate realistic interventions as the disease progresses. Living with a chronic illness encompasses acceptance, coping, self-management, integration, and adjustment (Ambrosio et al., 2015). Understanding these defining attributes will allow a person living with a chronic illness to develop a positive and healthy quality of life.

Chapter II: Literature Review

Systemic scleroderma is a destructive autoimmune connective tissue disease with debilitating and life-limiting physical and psychological effects. The purpose of this study was to explore the process of identity management in people living with systemic scleroderma. Systemic scleroderma is a chronic condition. Understanding the experience of living with a chronic illness and how this experience relates to systemic scleroderma is important to explore, as the understanding will reveal the underlying connection systemic scleroderma may have on an individual's identity.

The literature review for this study will begin by looking at the chronic illness experience broadly and will then move into the individual experience of living with systemic scleroderma. The chronic illness experience as it relates to systemic scleroderma, the impact of stigma, and the concept of loss of self will also be discussed. This literature review will conclude with a discussion focusing on the theoretical and philosophical perspectives supporting this study.

The Chronic Illness Experience

Living with a chronic illness is becoming more prevalent in the United States. Current statistics report that about half of all adults (117 million) are living with one or more chronic health conditions (CDC, 2016a). The CDC (2016a) reports there are about one in four adults living with two or more chronic health conditions. The terms disease and illness are many times used interchangeably; however, there is a distinct difference between these two terms. Disease refers to the fundamental cause or pathophysiology that is causing the change or destruction of a system in the body, for example diabetes, heart disease, or chronic obstructive pulmonary disease. Illness refers to the human experience of living with a particular disease (Larsen, 2013). An individual may experience the symptoms resulting from a given disease as debilitating and

causing pain and suffering. This experience is important to understand, as it provides insight into the lived experience of chronic illness management and is essential for how nurses provide care to individuals living with a chronic condition.

The World Health Organization's (WHO, 2005) definition of chronic illness is "a process of long duration and generally slow progression" that requires ongoing management over a period of years or decades (para. 1). Chronic illnesses persist indefinitely and can present in different ways. Chronic illness onset can be sudden or can be more insidious, taking many years before an individual begins to experience signs and symptoms. Sometimes chronic illness can go into remission; however, exacerbations and flare-ups are not uncommon as the chronic illness progresses. For some, a chronic illness can become fundamental to the person's identity (Larsen, 2013). Understanding the impact a chronic illness can have on an individual's identity is important and must be considered as an individual begins management of his or her chronic illness, as well as understanding an individual's perceptions and beliefs about living with a chronic illness.

Historically, chronic illness was a phenomenon studied by Glaser and Strauss (1975) and then by Corbin and Strauss (1988). In 1983, Charmaz began publishing significant work on chronic illness and the concept of loss of self. Much of Charmaz's work moved beyond the medical view of illness. Although individuals do experience physical symptoms and discomfort associated with many chronic diseases, for Charmaz (1983, 1995), the experience of suffering related to a destruction of one's self-image was seen as being more significant; much of *what was* is no longer. Over the duration of the illness trajectory of a chronic illness, Charmaz discovered that losses would accumulate without any new gains taking place. For Charmaz (1983), all of this added up to a diminished sense of self.

The experience of living with a chronic illness can best be described as a biographical disruption, where the individual experiences a break from the imagined normal continuity in life (Burles & Thomas, 2012; Clarke & Bennett, 2013; Hannum & Rubinstein, 2016; Joesey, 2016; Matthie, Hamilton, Wells & Jeneretta, 2016; Vallido et al.. 2010; Van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2015). There is a disconnect and disjuncture between what the individual is experiencing and how the chronic illness may impact their envisioned future plans.

Burles and Thomas (2012) conducted a phenomenological study with a purpose of trying to understand the role of life stages in someone with a chronic illness. The 10 participants in the study expressed how their symptoms were inconsistent with what they had envisioned their life to be as young adults; meaning, their life was unfolding differently than what they had expected. Themes that emerged from this study concentrated on how life was put on pause and how participants felt about the struggles of trying to integrate all of the uncertainties associated with their chronic illness and how these uncertainties related to the challenge of a changing identity (Burles & Thomas, 2012).

Through thematic analysis, Clarke and Bennett (2013) examined how 35 older adults experienced the physical and social realities of having multiple chronic conditions in their senior years. When comparing younger individuals with older individuals, both shared the experience of seeing their body and life change as they were living with a chronic illness. Although the elderly are generally more understanding and see chronic conditions as an expectation of getting older, both young and old people experience chronic conditions as being a personal disruption. When addressing social factors related to living with a chronic condition, themes revealed that

when discussing identity, men saw a threat to their identity as being more physical and women saw this threat as being more related to appearance (Clarke & Bennett, 2013).

Hannum and Rubinstein (2016) conducted a similar study using thematic analysis (n = 15). In their study, three main themes were identified from the data. *Biographical disruption* and *fragmented time* had the largest impact on participants' experiences. The main limitation of this study was that all participants were living with some form of cancer, instead of gathering experiences from a variety of chronic conditions. When comparing this study with other studies looking at the experience of living with a chronic condition, the findings aligned with the findings in other studies addressing the experience of living with a variety of different chronic conditions (Hannum & Rubinstein, 2016).

Matthie et al. (2016) investigated the perception of young individuals who had sickle cell disease. The 29 participants were African American adolescents and young adults ages 13 to 35. Through content analysis, four themes were identified: *struggling to maintain or achieve a good quality of life or life satisfaction*; *strategies to maintain self-care*; *interruptions to family, work, and social roles*; and *difficulties accessing needed health care*. Many of the struggles to maintain or achieve a good quality of life revolved around the mental and physical concerns of wanting to be normal and to do things their peers were doing. By far, the most meaningful findings were related to interruptions to family, work, and social roles (Matthie et al., 2016). The Hannum and Rubinstein (2016) study and the Matthie et al. study are important to individuals living with systemic scleroderma, because systemic scleroderma tends to affect young adults, and for this demographic, work, family, and social roles are important to one's sense of self and identity.

In a literature review (n = 13), Vallido et al. (2010) specifically looked at the role of mothering and how this role was affected by a chronic illness. Women who live with systemic

scleroderma tend to be between the ages of 18 and 40, with some also living with systemic scleroderma well into their 60s. The significance of Vallido et al.'s work is that it focused entirely on women who were in their childbearing years, when the mothering role is a significant component of one's identity. The purpose of this literature review was to examine qualitative empirical research investigating women's experiences of mothering disrupted by a chronic illness. The authors posited that motherhood is a primary identity for young women and that living with a chronic illness endangers the role and identity of motherhood. The mothering role is unique to women's identities, in that mothering gives women meaning, which means that this identity gives women a sense of safety and belonging (Vallido et al., 2010). It is interesting to note that even when these young to middle-aged women were physically present with their children, living with a chronic illness was seen as contributing to their sense of biographical disruption, because they felt their role of mother was interrupted by the illness and challenged that ability to fully carry out their mothering responsibilities. The most important of these responsibilities was to protect their children, which was threatened by their chronic illness. Having a chronic illness also threatened a woman's ability to fulfill her personal and social obligations to her children. Death was seen as the ultimate failure and disruption. Feelings of guilt and shame also strongly accompanied the sense of failure and disruption (Vallido et al., 2010). The main limitation to Vallido et al.'s qualitative literature review was that the women in the studies were separated by geography, socioeconomic status, level of marginalization, and the type of chronic disease itself. Having some consistency among these variables may have resulted in different findings.

Challenges to identity brought on by a chronic illness diagnosis are by far the most problematic to an individual's sense of worth and confidence. Van Gennip et al. (2015)

conducted a longitudinal study using thematic analysis (n = 19) to explore how the sense of personal dignity might change over time with the progression of a chronic disease. Three themes related to personal dignity emerged from the analysis. The theme of *dynamic equilibrium* revealed that having a chronic illness forced one to confront multiple changes in their lives. Some of these changes were seen as being immediate, while others were seen as being more of a progression over time. Participants in this study stated that the most significant threat to one's sense of dignity were losses resulting in changes to identity and role fulfillment. As their disease progressed, participants felt they were forced to surrender their roles and, subsequently, felt dependent on others (Van Gennip et al., 2015). The second theme of *downward trend* revealed that as their chronic illness became too much to endure, there was also a profound loss of dignity, where the individual stated they no longer felt worthy or useful. Van Gennip et al. established that experiencing a loss of personal dignity was linked to psychological suffering, which in turn may also contribute to a loss of self. The final theme that emerged was *stability*. Some individuals stated, even though they were living with a chronic illness, they were able to maintain their sense of dignity. They maintained their sense of dignity through strong religious beliefs, social position, and upbringing. It is important to note that in this study, few felt any sense of stability, and many of the participants struggled to maintain a sense of dignity (Van Gennip et al., 2015). The findings from this study are important to note and would be fundamental to understand in someone who is living with systemic scleroderma, because many of the same concerns may also be present in individuals living with systemic scleroderma.

The concept of uncertainty appears to be an important contribution to the experience of biographical disruption. To better understand how uncertainty impacts biographical disruption, Hoth et al. (2013) used linear mixed modeling to determine whether uncertainty had a larger

impact for patients as they were initially adjusting to their chronic illness or if uncertainty had a larger impact the longer they lived with their chronic illness. The 407 patients in this study were diagnosed and living with a chronic lung disease. Illness uncertainty was measured using the Mishel Uncertainty in Illness Scale for Adults. Within this instrument are the ambiguity and complexity subscales. The ambiguity subscale ($\alpha = .88$) looks at cues related to the state of the illness, asking whether the illness was getting better or worse. The complexity subscale ($\alpha = .79$) looks at cues related to treatment and navigating the healthcare system. Hoth et al. also were interested in understanding how depression, anxiety, and one's quality of life may also impact the feeling of uncertainty. Depression and anxiety were measured using the Hospital Anxiety and Depression Scale. The Cronbach's alpha for depression was .80 and the Cronbach's alpha for anxiety was .86. Health-related quality of life was measured using the St. George Respiratory Questionnaire ($\alpha = .94$). When looking at illness uncertainty, ambiguity was a higher significant predictor ($p < .001$) than complexity, depression, anxiety, or health-related quality of life. Other findings also indicated that the patients who felt a greater sense of ambiguity had worse outcomes. The length of time an individual lived with a chronic condition was not significant ($p > .05$) in relation to ambiguity or complexity. Findings also indicated that the number of years since diagnosis did not moderate the relationship between ambiguity and complexity with outcomes. To better understand how identity is affected by a chronic condition, Hoth et al. recommended that nurses focus on an individual's sense of ambiguity and help patients develop meaningful coping strategies to help lessen this sense of ambiguity and uncertainty.

Living with a chronic illness has been described as a biographical disruption of an individual's imagined or envisioned life plan. There is a disconnect that has both personal and social consequences. These struggles are real, and the uncertainties can be challenging to a

changing identity. Systemic scleroderma is a chronic disease that shares many of the same biographical disruptions that can impact an individual's quality of life as other chronic diseases.

Systemic Scleroderma and Clinical Manifestations

Systemic scleroderma is a chronic autoimmune connective tissue disease that is not well understood, despite the many advances that have been made. Systemic scleroderma is characterized by immunological cellular activation, vascular bed injury, and tissue and organ fibrosis (Bolster & Silver, 2011). There are two main classifications of scleroderma: limited and diffuse. Limited scleroderma is typically characterized by skin thickening limited to the distal areas of the elbows, knees, and face. Although limited scleroderma can be seen affecting the internal organs, it typically is not of the severe type. The diffuse type of scleroderma involves skin thickening of the distal elbows, knees, and face and involves severe internal multi-organ damage. There is no cure for individuals living with systemic scleroderma. Limited scleroderma can be managed more effectively; however, the progression of diffuse scleroderma will accelerate death due to the sclerosis of internal organs. Although there are several clinical manifestations seen in all individuals with scleroderma, a heterogeneous presentation of clinical presentation does exist, which can make the progression of scleroderma quite different for everyone (Bolster & Silver, 2011).

Some individuals living with limited scleroderma may also be referred to as having CREST syndrome, which is the former name given to limited scleroderma: (C) *calcinosis*, which refers to the calcium deposits found under the skin and in tissues; (R) *Raynaud's phenomenon,* which means that the tips of the fingers lose circulation and become cyanotic; (E) *esophageal dysmotility,* which affects the esophagus causing heartburn; (S) *sclerodactyly,* which means the skin on the tips of the fingers becomes thick, making it difficult to feel or grasp anything; and (T)

telangiectasias, which refers to enlarged blood vessels that can appear to look like big red spots on the face and other areas on the body (Cleveland Clinic, 2017; Johns Hopkins Medicine, 2017).

Incidence and Prevalence

Incidence and prevalence rates (number of new and total cases) vary greatly and tend to be dependent on geographical location (Barnes & Mayes, 2013). Several of these differences may be due to environmental exposures, which may trigger genetic susceptibility (Barnes & Mayes, 2013). Annual incidence of scleroderma in the United States is approximately 20 cases per one million adults, with a prevalence of approximately 240 cases per one million. Women are four times as likely as men to develop systemic scleroderma, with the age of onset being between 30 and 40 years of age, with some being younger (Cleveland Clinic, 2017).

Risk Factors

Risk factors associated with systemic scleroderma include gender, race, age, family history, birth order, and environmental factors. It is interesting to note that gender does seem to be one of the most significant risk factors associated with systemic scleroderma. The hypothesis is that this difference may be related to hormones, pregnancy-related events, or events that seem to be gender specific to environmental exposure factors (Barnes & Mayes, 2013).

Mortality

Survival is dependent on the level of internal organ damage, where the average 10-year survival rate is about 70% to 80%. This is mostly due to advances in research and newer medications. However, there is still a poor prognosis for individuals with diffuse scleroderma. Death is typically due to pulmonary fibrosis with pulmonary hypertension, with severe gastrointestinal and heart disease as secondary causes of death (Cleveland Clinic, 2107).

The Chronic Illness Experience as It Relates to Systemic Scleroderma

Systemic scleroderma is a rare autoimmune condition that shares many of the same characteristics associated with having a chronic illness; however, there are many characteristics unique to someone living with systemic scleroderma. One of the most prominent concerns for individuals living with systemic scleroderma involves changes to physical appearance, especially to the face (Joachim & Acorn, 2003; Nakayama et al., 2016; Oksel & Gunduzoglu, 2014). These changes can be emotionally distressing and stigmatizing.

The concepts of biographical disruption, uncertainty, insecurity, and loss are basic primary concerns related to the experience of living with systemic scleroderma. All of these concepts align and support the general findings associated with the experience of living with a chronic condition. Joachim and Acorn (2003) were interested in understanding the individual experience of living with scleroderma. Joachim and Acorn held focus groups with 13 women who had been living with scleroderma between five and 17 years (average 10.8 years). The researchers asked the participants to describe what it was like to have scleroderma. Included in the discussion were questions on whether the women told others about their scleroderma, and if so, what factors helped them to decide to disclose that they had scleroderma, along with how scleroderma affected their lives and what information they wished nurses would know about someone living with scleroderma. Joachim and Acorn used thematic analysis to analyze the transcripts, and five themes were identified: *physical manifestation, disclosure/non-disclosure, living with scleroderma, being normal, and facing the future.*

Under the theme physical manifestations, physical symptoms were paramount (Joachim & Acorn, 2003). In the beginning stages, Raynaud's phenomenon and ensuing arthritis were the most distressing, followed by declining fine motor skills and tightening of the skin, especially

around the mouth (Joachim & Acorn, 2003). When discussing whether to disclose they had scleroderma, disclosure was done strategically, because they did not want to be treated differently and draw undue attention. The perception of stigma was a concern to the participants, and they only disclosed they had scleroderma to people they could trust and who were genuinely interested. Living with scleroderma emphasized feelings of uncertainty and unpredictability and encompassed the disease progression and how this progression would bring about the loss of things and roles that they no longer could do (Joachim & Acorn, 2003).

Living with scleroderma also included concerns around physical appearance (Joachim & Acorn, 2003). Many of the women were worried about how their body was going to deteriorate visually, which included facial distortion, and that they would not be able to recognize themselves. One participant expressed how she hoped that she would die before she did not recognize herself. Others expressed they wanted to die before they became *ugly*. Uncertainty was a main concern under the theme of facing the future. Participants expressed how difficult it was to plan for the future, primarily because they did not know how scleroderma would affect them. The theme being normal meant trying to maintain a healthy self-image. The capacity to cope was a strength that helped participants maintain a sense of reality. Trying to live a normal life as much as possible was also a healthy coping mechanism. For all participants in this study, scleroderma impacted their daily lives and activities of daily living (ADLs; Joachim & Acorn, 2003). Since scleroderma is a rare disease, and many healthcare practitioners have little knowledge about scleroderma, participants wanted nurses to be better informed about scleroderma and how this disease affects them. Fears around social isolation and social rejection also contributed to their feelings of stigmatization. Although this study was published in 2003, many of the findings do support Oksel and Gunduzoglu (2014), who also looked at the

experience of living with scleroderma. A limitation to the Joachim and Acron (2003) study is that all the participants were women and the experiences of men were missing.

Oksel and Gunduzoglu (2014) researched the experience of 20 Turkish women living with scleroderma. Many of the same characteristics associated with living with a chronic condition were also evident in this study; however, this study elucidated the struggles that women living with scleroderma had living and performing their expected roles. Oksel and Gunduzoglu used an exploratory-descriptive phenomenological approach, which revealed four main themes: *self-perception*, *roles in relationships*, *activities and exercise*, and *sexuality*. The women in this study had been living with scleroderma for an average of eight years (Oksel & Gunduzoglu, 2014).

Oksel and Gunduzoglu (2014) found that self-esteem disturbances, fear, and anxiety all contributed to the female participants' stress. Feeling pessimistic, scared, and alone contributed to a negative self-perception. Adding to their sense of stress and negative self-perception was how the women in this study felt about their distorted appearance. Oksel and Gunduzoglu noted that participants expressed disbelief at how quickly they changed. Fatigue, physical limitations, and activity intolerance were significant under the theme of activity and exercise. Participants expressed how they did not feel free and how scleroderma restricted their movements, which in turn affected their intolerance to activity and exercise. In reference to the theme of sexuality, having scleroderma disrupted their sexual life. This disruption affected the women emotionally, which in turn affected their partner's attitude toward them. Feeling estranged from their husbands and not being considered a *woman* were significant emotional stressors that also added to their negative sense of self-perception. The final theme, role in relationships, was revealing (Oksel & Gunduzoglu, 2014). Social and cultural roles tend to inform one or more of a woman's

roles and responsibilities (Azmitia, 2015). The women stated how their roles were disrupted by having scleroderma. The most important roles of mother and spouse brought about feelings of being insufficient; furthermore, the constant need to explain themselves as to why they could not carry out these roles brought on feelings of isolation (Oksel & Gunduzoglu, 2014).

Oksel and Gunduzoglu (2014) elucidated the importance of how chronic diseases, specifically scleroderma, can change people in several ways. Stress changes in one's appearance, quality of life, and expected roles can affect one's self-concept and self-respect, which in turn can have an effect on one's identity. One limitation of this study is that it focused on the experiences of women living with scleroderma, but did not include experiences of men living with scleroderma. This study was carried out in Turkey, and the social and cultural norms embedded within Turkish society may have influenced the participants' responses. Findings in this study may be difficult to transfer to the experiences of women living with scleroderma in the United States.

Gumuchian et al. (2016) used focus group interviews to gain in-depth understanding of the emotional experiences and the sources of emotional distress for women and men living with scleroderma. Twenty-two participants were part of this study (18 females, four males), with an age range between 26 and 77 (mean = 53, SD = 10) and an average length of time living with scleroderma of eight years. Two participants were diagnosed with limited scleroderma, 10 with diffuse scleroderma, five with CREST, and five who were unsure of their type of scleroderma. Using thematic analysis, six themes were identified: *facing a new reality*; *the daily struggle of living with scleroderma*; *handling work, employment, and general financial burden*; *changing family roles*; *social interactions*; and *navigating the health system* (Gumuchian et al., 2016).

Facing a new reality focused on the feelings of unpredictability and uncertainty, which also included reevaluating one's role (Gumuchian et al., 2016). Two main events shaped these feelings: the experience of having to endure symptoms of scleroderma before ever being officially diagnosed with scleroderma and once diagnosed with scleroderma, coming to terms with the diagnosis (Gumuchian et al., 2016). The second theme was the daily struggle of living with scleroderma. Under this theme, participants revealed their feelings of hopelessness and guilt. Much of the feelings of hopelessness focused on trying to manage the psychological burden associated with the physical symptoms and the physical appearance. Fatigue was the main symptom that made it impossible for participants to carry out their daily obligations, which led to feelings of guilt. The reality of a changing appearance was also something that contributed to feelings of hopelessness. Having scleroderma eventually impacted the ability to work and maintain a career. This was a common experience for participants in the third theme of work, employment, and general financial burden (Gumuchian et al., 2016).

The fourth and fifth themes of changing family roles and social interactions revealed feelings of emotional distress (Gumuchian et al., 2016). While some participants' families were supportive, other families were not. What contributed to some families not being as supportive was the difficulty of the person with scleroderma to convey to family members how they were actually feeling and how scleroderma was affecting them. Women, in particular, expressed feelings of guilt and worry because of their role as the primary caretaker and not being able to fully participate or fulfill that role, which made the women in this study feel as though they were letting the family down. Having scleroderma caused emotional distress, because participants felt labeled and singled out for being different and being unable to do things that others typically were able to do, causing feelings of social isolation (Gumuchian et al., 2016).

One limitation to Gumuchian et al.'s (2016) study is that this study was primarily about the experiences of women living with scleroderma. Only four men participated of this study, and the unique experiences of men living with scleroderma might not have been captured, especially when using focus groups. The men might not have been as comfortable revealing exactly how they were feeling in front of a group made up primarily of women. Another limitation of this study was that recruitment was at one hospital using convenience sampling. The findings from this study may have also captured certain characteristics particular to this hospital or individuals who use this hospital for their care. The findings, therefore, might not transfer to the experiences of others living with scleroderma outside this clinical setting (Gumuchian et al., 2016).

In a quantitative study, Cinar et al. (2013) used a descriptive, cross-sectional design to determine the challenges and coping strategies experienced by 19 women whose hands were affected by systemic scleroderma and the effect this had on performing ADLs. Mean age of the subjects was 49 years, with a standard deviation of nine years. Cinar et al. collected data using the UK Scleroderma Functional Questionnaire (UKFS) and the Evaluation of Daily Activity Questionnaire (EDAQ). The UKFS is an 11-item questionnaire looking at both upper and lower extremity use, as well as muscle weakness. The UKFS is scored at the ordinal level, where subjects can rate (0 to 3) their function based on if they can perform a certain muscle activity. The EDAQ is a 102-item questionnaire that measures perceived difficulty performing certain ADLs with and without the use of assistive devices. The EDAQ is scored using the ordinal level of measurement, where subjects can rate (0 to 3) their perceived performance difficulty. The researchers used a Spearman rho correlation to test the linear association between EDAQ score and the functional score, skin score, and disease duration. There was no significant correlation between total EDAQ scores, functional scores, skin scores, and disease duration of subjects with

diffuse and limited scleroderma. While statistical significance was again not reached, Cinar et al. indicated that the strongest correlations were between total EDAQ and disease duration (p = .414, p = 0.273) and total EDAQ score and total skin score (p = 0.488, p = 0.153). Limitations to this study place the results in question. There were no Cronbach's alphas reported, which questions the internal validity of these instruments. The sample size of 19 was small, and one should use caution when generalizing the findings to the scleroderma population. Finally, as this study was conducted in Turkey, responses reflect the cultural and social norms of individuals living in Turkey. The idea of social support, a concept taken from this study, is typically seen as something positive and an expected social norm in Turkey; whereas, Western culture emphasizes independence. However, both cultures do view becoming dependent on others as somewhat of a burden and as a loss of autonomy. One of the most distressing coping strategies discovered in this study was that when scleroderma progresses to a point where the individual is not able to perform basic ADLs, they tend to relinquish their independence to others or eventually avoid those activities, thus bringing about a sense of loss of self (Cinar et al., 2013).

The concepts of biographical disruption, uncertainty, insecurity, and social isolation are major distresses for individuals living with scleroderma. The strengths of these studies are that they have a strong representation of women living with scleroderma, and many of the studies used either focus groups or phenomenology to capture the experience of living with scleroderma. The limitations are that the unique experiences of men living with scleroderma were not represented nor was there an equal representation of race and ethnicity. The most recent studies on the experience of living with scleroderma are from outside the United States, which intrinsically may embed cultural norms and experiences unique to those individuals. The average length of time living with scleroderma is eight years. There are no current studies using grounded

theory to explore the social process of living with scleroderma. The limitations of the body of literature reviewed provide an opportunity to explore the experience of living with scleroderma using grounded theory.

Stigma

The impact of stigma on an individual living with a chronic illness can have a negative effect. Goffman (1963) did some groundbreaking work investigating how stigma impacted social identity. His work continues to influence current research on stigma. As stigma is socially constructed, it can mean something different to each individual and can vary from situation and setting (Stuenkel & Wong, 2013). Society instills or teaches individuals to place people into categories based upon common attributes (Goffmanm 1963) or what Stets and Burke (2000) coined as *in-groups* and *out-groups*. Goffman noted that acquiring and maintaining a social identity does not only include personal attributes, but also includes one's role in society, which in turn contributes to one's sense of self. Stigma results when individuals are made aware of their undesirable differences and are excluded from society (Goffman, 1953).

Recent studies incorporating Goffman's (1963) work on stigma include the concept of intersectionality (Caiola, Docherty, Relf, & Barroso, 2014; Earnshaw, Bogart, Dovidio, & Williams, 2015; Ghabrial, 2017; Mora-Rios, 2016). Intersectionality takes into consideration the social constructs of race, gender, ethnicity, social class, and sexuality and understanding how these social constructs are layered within an individual's experience (Caiola et al., 2014). Stigma can have a deeper meaning when one begins to understand the influence of these social constructs.

Stigma has a strong influence on acceptance and disapproval of a person or group based upon expected behavior and personal attributes. If you do not fit in, society has a way of

labeling, discriminating, and devaluing based upon unaccepted behaviors or attributes that do not conform to the expected norm (Burke & Stets, 2009; Goffman, 1963; Stryker & Burke, 2000). Stigma is so powerful that it may also reveal negative changes in one's perception of body image and induce feelings of social isolation, loss of social status, and a decreased sense of personal control (Stuenkel & Wong, 2013).

Goffman (1963) identified three types of stigma: physical deformity, character blemishes, and prejudice. Physical deformity is identified by any physical abnormality that is seen as being out of the expected physical norm. Individuals who might experience this type of stigma might be individuals who have a physical disfigurement resulting from a serious burn, deformities from rheumatoid arthritis, or physical disfigurement from systemic scleroderma. Stigma resulting from a character blemish typically results from conditions that are seen as being self-imposed. Individuals, typically, are blamed for a physical or psychological condition seen as something that could have been prevented, but as a result of individual behavior has been acquired, for example, HIV/AIDS or most recently human papilloma virus. Prejudice is the third type of stigma and has its foundation rooted in cultural, social, or religious beliefs and values. Individuals are seen as less valuable and unworthy because of some deviation from a set of values or mores set by a society or subset of a society. All three types of stigma eventually prevent an individual from participating in society based upon some undesirable or unwanted trait, and all three have the potential to overlap with one another (Goffman, 1963).

According to Goffman (1963), stigma can also be felt and enacted. Felt stigma is an internalized sense of feeling devalued or not meeting social expectations. As a result, the individual may begin to react to the worry of being treated differently. Enacted stigma is a result of behaviors that others enact onto the individual, with the intent of making that person feel

different or devalued or not belonging to the group. Just as the three types of stigma can overlap, so can felt and enacted stigma overlap (Goffman, 1963).

Berger, Kapella, and Larson (2011) qualitatively looked at stigma in 16 individuals living with chronic obstructive pulmonary disease (COPD). The purpose of their study was to understand the experience of stigma in COPD. Through content analysis, two main categories were identified: perceptions of COPD-related stigma and people's responses to stigma. Participants were aware of the perceptions of stigma and were aware of how relationships interacted with the sense of perceived stigma. For individuals who had a close relationship with family or friends, the more accepted and supported they felt, as well as less stigma. Participants who interacted more with strangers reported they felt a sense of uncertainty and an increase in stigma, primarily because they did not know how they would be seen and treated because of their COPD and the signs and symptoms associated with COPD (Berger et al., 2011).

Under the category of people's response to stigma, blame was the predominant sentiment. Individuals in Berger et al.'s (2011) study had COPD, and the number one cause of COPD is smoking (CDC, 2016b). Participants stated they blamed themselves for having COPD, because the majority admitted to smoking. The participants also felt this sense of blame from their healthcare providers. When discussing their physical and functional limitations, most participants reported they felt their sense of self-worth was diminished because of their physical and functional limitations. Having to wear oxygen continuously and not being able to walk as far as their peers could walk made them feel as though they were a burden and that others needed to make accommodation for them. In an effort to avoid stigma, most participants stated they just did not want to socialize with others, and if they could, they would make an attempt to not use their oxygen around others, so they would not feel out of the ordinary. Berger et al.'s study

supports Goffman's (1963) work, and the concept of felt stigma still exists and is an important factor for someone living with a physical chronic illness. One major limitation to the Berger et al. study is that the study specifically looked at individuals with COPD, which is a physical condition that can manifest itself with physical limitations. Systemic scleroderma is unique in that the physical symptoms include other visible physical deformities, and the stigma experienced by individuals with systemic scleroderma may be quite different from the stigma experienced by individuals with COPD.

Lebel et al. (2013) were interested in understanding stigma and the psychosocial impact that stigma might have for individuals with head and neck cancer and lung cancer. Lebel et al. used a naturalistic, cross-sectional design (n = 206). The purpose of Lebel et al.'s study was to investigate relationships between stigma and distress and subjective wellbeing in lung or head and neck cancer from the perspective of the Illness Intrusive Framework. The Illness Intrusive Framework, by Devins, Bezjak, Mah, Loblaw, and Gotowiec (2006), posits that disruptions in one's lifestyle induced by a chronic illness undermine quality of life and that quality of life can be moderated by social and psychological factors. A limitation to using a naturalistic, cross-sectional design is that this type of design makes it difficult to make any firm, causal interpretations of the findings.

Lebel et al. (2013) measured psychological distress using the Affect Balance Scale (α = .72) and the Center for Epidemiological Studies Depression Scale (α = .90). The Explanatory Model Interview Catalogue (EMIC, α = .82) is a 4-point Likert scale and was used to measure stigma across both mental and physical illness. The Illness Intrusiveness Scale was used to measure illness-induced disruptions in relation to certain activities. This instrument has three subsections, with a total Cronbach's alpha of .88. Disfigurement was measured using the

Disfigurement Scale (α = .67), which is a 6-item, self-report scale. A Pearson's correlation revealed that individuals who reported high levels of stigma also reported high levels of distress ($r = .44$, $p < .01$), high levels of illness intrusiveness ($r = .46$, $p < .01$), and high levels of disfigurement ($r = .43$, $p < .01$). Hierarchical multiple regression analysis revealed that cancer site ($\beta = 0.16$, $p < 0.05$) and disfigurement ($\beta = 0.54$, $p < 0.001$) were significant predictors of stigma (Lebel et al., 2013).

Benefit-finding is a term used to find positive changes that may result from the experiences of living with a chronic illness (Tennen & Affleck, 2002). Lebel et al. (2013) measured benefit-finding using the Post-Traumatic Growth Inventory (α = .94). This 21-item scale is widely used with individuals living with cancer. Hierarchical multiple regression analysis revealed that benefit-finding was not a significant predictor of stigma ($\beta = -0.04$, $p < 0.001$); in other words, benefit-finding increased subjective wellbeing and decreased the experience of reported stigma. What Lebel et al. also revealed was that benefit-finding moderated the impact of stigma on subjective wellbeing, but not on distress. It was also revealed that illness intrusiveness partially mediated the psychosocial impact of stigma for both distress and subjective wellbeing (Lebel et al., 2013).

Lebel et al. (2013) investigated felt stigma by looking at self-blame and disfigurement. People with lung cancer tend to report more self-blame, because the cause of their lung cancer was seen as something they inflicted on themselves. Those with head and neck cancer tend to report less self-blame; however, those with head and neck cancer reported higher levels of disfigurement, which increased their levels of reported felt stigma. This study also supports the work by Goffman (1963) and his findings related to felt stigma. In this study, benefit-finding appeared to be the most significant factor as a coping strategy for positive psychological

adjustment related to stigma (Lebel et al., 2013). Individuals with systemic scleroderma also experience disfigurement. Although this study looked at individuals with head and neck disfigurement resulting from cancer, one could hypothesize that similar findings related to stigma may be found with individuals living with systemic scleroderma.

In a similar study, Earnshaw, Quinn, and Park (2011) investigated anticipated stigma and how social support may reduce the sense of stigma individuals might be feeling. Earnshaw et al. included individuals with a variety of chronic illnesses, for example inflammatory bowel disease, muscular sclerosis, fibromyalgia, epilepsy, and lupus. The purpose of this quantitative study was to examine the process by which anticipated stigma related to quality of life among people with a chronic illness. The age range for the 172 participants in this study was between 18 and 78 years, with a mean age of 40 years. The sample mainly represented White, married females.

Earnshow et al. (2011) tested three hypotheses using path analysis. The first hypothesis was that stress mediates the relationship between anticipated stigma from family and friends, work colleagues, and health workers with quality of life. The second hypothesis was that social support mediates the relationship between anticipated stigma from family and friends and work colleagues and quality of life. The third hypothesis was that patient satisfaction mediates the relationship between anticipated stigma from healthcare workers and quality of life. The Chronic Illness Anticipated Stigma Scale (CIASS, $\alpha = .91$) was used to capture to what extent patients anticipated stigma from friends, family, work colleagues, and healthcare workers. Earnshow et al. used a Likert scale, where patients rated their responses between *very unlikely* and *very likely*. Perceived stress was measured using the Perceived Stress Scale (PSS, $\alpha = .91$), which captured data related to how much stress patients felt in their personal life they felt was unpredictable and uncontrollable, as well as how overloaded they felt their life was. The participants rated their

responses between *never* and *very often*. Perceptions of the amount of emotional and instrumental support patients received from others was measured using the Multidimensional Scale of Perceived Social Support (α = .90). A Likert scale captured patient responses between *strongly disagree* and *strongly agree*. How satisfied patients were with their healthcare provider was measured using the Primary Care Provider Questionnaire (α = .91). A Likert scale was used to capture patients' responses between *strongly disagree* and *strongly agree*. Quality of life was measured using the brief version of the WHO's Quality of Life Scale (WHO-QOL, α = .93). A Likert scale was used to capture patients' responses between *not at all* and *completely*.

Earnshow et al. (2011) found that patients often anticipated various amounts of stigma from each source, with the least amount of anticipated stigma coming from friends and family and the most anticipated stigma coming from work colleagues. However, if patients did anticipate greater stigma from family and friends and work colleagues, they also reported greater amounts of stress in their lives and reported having a lower quality of life. The entire model for the path analysis accounted for 60% of the variance in patient quality of life. Earnshow et al. found that stress and social support fully mediated the relationship between anticipated stigma from friends and family and quality of life. When synthesizing the findings of this study, the most important finding was that people living with a serious chronic illness do not actually need to experience enacted stigma in order to experience negative outcomes associated with stigma affecting their daily lives and quality of life. This study revealed that all individuals need to do is to believe that they may experience stigma, and this internalized felt stigma can affect their quality of life (Earnshow et al., 2011).

Brown (2015) found that the greater one's functional limitation, the greater one's perceived self-stigma. The purpose of Brown's study was to examine the extent to which

variation in perceived stigma associated with chronic health conditions is influenced by age, stress, and psychosocial resources (n = 417). Functional limitation was included as one of the stressors. Brown used stratified random sampling, with subjects completing two interviews three years apart from each other. Subjects' ages ranged between 20 and 93 years (median age = 59). The PSS (α = .91) was used to assess feelings of devaluation associated with physical limitations. This scale specifically includes questions related to functional status. To investigate physical limitation further, Brown used the Level of Functional Limitation Scale (α = .91) to measure physical mobility, instrumental daily activities, and basic ADLs. This scale provides a comprehensive look at an individual's total functional ability. The scale is constructed using a Likert scale, ranging from *not at all* to *completely*.

Brown (2015) measured stress using the Stressor Exposure Scale, which includes several questions related to major and recent life events. A comprehensive score is based upon how many questions the individual identifies as being a major stressor. The higher the score, the more stressors identified. Social support, mastery, and self-esteem were three items that looked at psychosocial resources. The Provisions of Social Support Scale (α = .91) was used to measure social support. This scale was based on a Likert scale, where subjects could choose between *very true* and *not true at all*. Mastery (the extent to which you feel that you have control over events in your life, if you feel that you are able to solve these problems, feeling pushed around, and how you feel about the future) was measured using the Mastery Scale (α = .78), which is a 7-item Likert scale, where subjects could choose between *strongly disagree* and *strongly agree*. The Self-Esteem Scale (α = .70) was used to measure how you feel you compare to others based upon one's sense of self-worth and the number of *good* qualities that you feel you have. Included in

this scale is how much you feel that you are a failure. In this Likert scale, subjects could choose between *strongly disagree* and *strongly agree*.

Brown (2015) used residual change regression to analyze the changes in perceived stigma over a 3-year period between wave 1 and wave 2. Findings revealed that perceived stigma is positively correlated with level of functional ability (.239; $p < .05$) and experience of major life events (.143; $p < .05$,) and negatively correlated with mastery (-.174; $p < .05$) and self-esteem (-.187; $p < .05$). Perceived self-stigma is decreased when one feels they can master or overcome limitations that may be imposed as a result of having a chronic condition, because physical health conditions (limitations) can make one feel socially incompetent and possibly invaluable (Brown, 2015).

Several limitations to the Brown (2015) study include that the subjects were recruited from one local area in Florida, which might influence the results based upon regional differences and also makes it difficult to generalize findings to the general population. The Cronbach's alphas on several of the instruments was not strong, which calls into question if the results actually represent the findings.

Many of the studies above on chronic illness and stigma support and give strength to the study discussed earlier by Joachim and Acorn (2003), where the researchers looked at the experience of living with scleroderma. Their findings related to physical manifestations of symptoms, not wanting any undue attention and not wanting to be treated any differently, address how strong stigma (either felt or enacted) affects the experience of living with scleroderma (Joachim & Acron, 2003). The sense of loss, uncertainty, and changing roles also address the ever-changing conditions related to the experience of living with scleroderma.

Society has a way of labeling people as less valuable and unworthy if societal norms are not adhered to. Stigma can have a strong influence on this labeling. Stigma does not need to be enacted in order for an individual to experience the negative effects of stigma. Chronic illness can carry stigma with it, and individuals living with scleroderma can undeniably feel the effects of stigma.

Most of the studies looked at both felt and enacted stigma, and all of these studies looked at stigma from the perspective of various chronic conditions. A majority of the studies were quantitative, using a cross-sectional, correlational design. One study used a qualitative approach to understand the experience of stigma and used content analysis. Many of the instruments had high Cronbach alphas and captured the psychosocial impact of stigma. The limitations to the current body of work on stigma in this literature review indicate that there is a need for more qualitative studies looking at the lived experience of stigma as it relates to chronic illness. A second limitation is that there are no current studies looking at stigma specifically related to scleroderma. Most chronic illnesses are not as disfiguring as scleroderma; in fact, most chronic illnesses are not obvious to others. More studies need to look at the connection between disfigurement and stigma and how functional limitations and social roles affect stigma.

The Concept of Identity and Factors Associated with Identity and Loss of Self in Persons Living with Scleroderma

The concept of identity can be traced backed to early philosophy and the enlightenment era and the work of Descartes (1637/2000), where his most famous words *Cogito, ergo, sum* (I think, therefore I am) recognized the consciousness of existence. Other philosophers, such as Locke (1694/1998), Hume (1739/1986), and Kant (1781/2007), have also discussed the concept of identity. Moving from philosophy to psychology and sociology, two of the earliest and most

influential identity theorists were William James (1890), who saw identity as consciousness of sameness, and George Herbert Mead (1934), who saw identity as being socially constructed. One of psychology's contemporary identity theorists is Erik Erikson (1950, 1968), who studied the development of identity throughout the lifespan. Since then, the concept of identity has developed and evolved to include identity as it relates to individual roles (McCall & Simmons, 1966), gender (Bem, 1981), culture (Collier & Thomas, 1988), and stigma (Goffman, 1963).

Identity is an internal process where the *I* becomes *me* and the self is constructed (James, 1890; Waterman, 2015). This internal process is influenced by personal experience and social categories, and these categories socialize us into groups with expected roles and behaviors. Living with a chronic illness, such as systemic scleroderma, the self can quickly become deconstructed, and one is forced to examine identity in the reality of living with a chronic illness, for example, individuals living with systemic scleroderma.

No published studies were found that specifically looked at identity and systemic scleroderma. Most studies related to systemic scleroderma focus on understanding the cellular, molecular, and genetic factors in hopes of one day finding a cure for this autoimmune connective tissue disease. When searching for studies related to the experience of living with systemic scleroderma or scleroderma, there were several factors those living with systemic scleroderma shared, which included physical concerns related to the manifestation of symptoms and the psychological and social concerns related to stigma, self-image, uncertainty, sense of a loss of self, isolation, and a disruption of expected roles (Benrud-Larson et al., 2003; Buck, Poole, & Mendelson, 2010; Gumuchian et al., 2016; Hornboonherm, Nanagara, Kochamat, & Wantha, 2016; Jewett, Hudson, Malcarne, Baron, & Thombs, 2012; Joachim & Acorn, 2003; Oksel & Gunduzoglu, 2014). All these factors demonstrate a loss of the self or a disruption of what used

to be stable and recognizable (sameness). Although not explicitly stated in the scleroderma literature, many of these factors are closely related to the concept of identity.

Theoretical and Philosophical Perspectives Supporting the Study

There are several theories and models supporting this study, all of which complement each other and give strength to the underlying purpose of this study.

Social Identity Theory and Role Identity Theory

The concept of identity has been shaped over the years by both social identity theory (Tajfel & Turner, 1986) and role identity theory (McCall & Simmons, 1966). Both theories are closely interrelated and will be discussed together. Human beings bring meaning to almost everything they interact with, whether it is an object or a social interaction. Individuals are constantly identifying, naming, and categorizing in an attempt to understand who they are and where they belong (Hammack, 2015). When studying identity, it can be said that it is the "anchoring concept for thinking about difference and sameness" (Hammack, 2015, p. 11). This difference and sameness is played out whenever we look at social categorization, group affiliation, or intergroup relationships (Hammack, 2015).

Identity has been studied as a culture, a common collective social inclusivity, or as a part of the person with specific roles that have meaning (Stets & Burke, 2000; Stryker & Burke, 2000). Burke and his colleagues hold to the latter definition. The core processes for both social identity theory and role identity theory involve both a cognitive process and a motivational process. The cognitive process for social identity theory is called depersonalization and the motivational process is called self-esteem. For identity theory, the cognitive process is called self-verification and the motivational process is called self-efficacy (Stets & Burke, 2000; Stryker & Burke, 2000).

The concept of identity has its foundation based upon the distinction between *I* and *me* (I/me). The *me* is the outside projection of who you are, basically what is visible to others, and contains social and cultural knowledge; while, the *I* is what is private and interior, which makes up the *self,* and there is a negotiation that takes place between the two (Burke & Stets, 2009; Hammack, 2015).

Depersonalization is when a person focuses on a particular group and forms his or her identity based upon the categories associated with that group, otherwise known as group-based. Within this process, individuals tend to self-stereotype and take on the values, beliefs, and behaviors of that group (Burke & Stets, 2009; Stets & Burke, 2000; Stryker & Burke, 2000). Cognitively, they see themselves as the *in group* and separate themselves from the *out group,* whose values, beliefs, and behaviors are perceived to be different from the *in group.* Thus, individuals who follow social identity theory are actually seen as being part of a highly structured categorical society. This process is also called self-categorization. By doing this, one can develop strong self-esteem.

In social identity theory, self-verification is when an individual sees themselves as taking on a specific role within society, and this role becomes incorporated into the self (identification), with the role having meaning and expectations, which in turn, guides behavior (Burke & Stets, 2009; Stets & Burke, 2000; Stryker & Burke, 2000). Burke and his colleagues posited that identities can be seen as a type of schema that helps to commit to an expected behavior based upon internalized roles and the relationships that an individual has with others (Hammack, 2015; Stryker & Burke, 2000). People do not have just one or two roles, but many roles that make up who they are. These roles are organized within a hierarchy, which can change in priority depending upon which role or roles are most salient at the current time. Several of these roles can

actually be acted out simultaneously. In role-based identity theory, individuals negotiate roles with each other; for example, two individuals may be acting out the same role, but the meaning that each has associated with that role can be slightly different. For role-based identities, relationships between individuals are seen as being reciprocal, and they enjoy the interconnected uniqueness between one another (Burke & Stets, 2009; Stets & Burke, 2000). The importance is not how similar someone is to the group, but rather how individual and interconnected someone is to others and the importance of the complex interrelatedness of a social structure (Burke & Stets, 2009; Stets & Burke, 2000). By doing this, one can develop a strong sense of self-efficacy.

Identity salience is associated with the activation of an identity. Salience can be defined as when someone is either "functioning psychologically to increase the influence of one's membership in that group on perception and behaviors," as in social identity theory, or from the identity theory perspective as "the probability that an identity will be activated in a situation" (Stets & Burke, 2000, p. 229). Accessibility and fit are important for normative identity development in social identity theory. When an individual is ready to take on certain categories that are significant to the group (accessibility), there is a fit between these goals and the membership of the group. When accessibility and fit are met, the individual is seen as having activated his or her commitment to identity salience (Stets & Burke, 2000).

Identity salience and commitment for social identity theory is seen as having two qualities that encompass both breadth and depth (Stets & Burke, 2000). The first aspect concerns the number of individuals that someone is connected to through their identity (role). The more people that subscribe to the same role identity as the individual, the greater the identity is embedded within the cognitive framework of that individual, and the role will be activated. The second aspect refers to how strong these ties are to others who share the same role. The stronger

these ties are, the more salient the behavior, thus commitment and activation (Stets & Burke, 2000).

Vallido et al.'s (2010) study looked at the role of mothering, and how this very unique, specific role contributes to identity supports the idea that specific roles have meaning and that meaningful roles contribute to one's sense of identity and self-verification (Stets & Burke, 2000; Stryker & Burke, 2000). Van Gennip et al. (2015) also supported the concept of meaningful roles and how these meaningful roles are connected to one's sense of dignity and identity. Some of the most profound losses related to living with a chronic illness resulted in significant changes to one's identity and role fulfillment. In the scleroderma literature, one of the findings was related to one's role in relationships (Oksel & Gunduzoglu, 2014) and how this disruption or loss of one's role led to feelings of being insufficient and always having to explain to others or having to convince yourself how you are fulfilling your role. The scleroderma and stigma literature clearly demonstrated the concepts of sameness and difference (Hammack, 2015) and how these two concepts related to social categorization, group affiliation, and identity.

Common Sense Model

The common sense model (CSM) posits that individuals gather concrete and abstract pieces of information related to an illness and create a mental image or representation of that illness. By creating this mental representation, the individual is then able to make sense of that illness and thus be able to manage the illness (Hagger & Orbell, 2003; Leventhal, Nerenz, & Steele, 1984). There are three initial sources of information that contribute to the interpretation of an illness, and these three sources combine social and personal information in order to create a mental representation.

The first source of information comes from what has already been assimilated and interpreted into an individual's cognitive framework from long-term prior social communication and interaction related to a particular illness (Hagger & Orbell, 2003; Diefenbach & Leventhal, 1996). Some of this information may include one's personality type and have a strong cultural influence. The second source of information comes from external influences within the individual's social environment, in which the individual has come to perceive as being an important part of their life. These important people can be parents, friends, significant others, or authority figures, such as physicians and therapists. The third source of information comes from the direct existing signs and symptoms the individual is experiencing from the illness. This current experience can also include previous experiences of an illness and the coping mechanisms that were effective in managing those symptoms (Hagger & Orbell, 2003; Diefenbach & Leventhal, 1996). When you combine all three sources, they contribute to how an individual makes sense of their illness. In the CSM, these perceptions and interpretations lead to illness representation. Diefenbach and Leventhal (1996) hypothesized that making sense equates to common sense.

Cognitive interpretation of illness within the CSM includes four dimensions: cause, consequences, identity, and timeline (Hagger & Orbell, 2003). The cause dimension aligns with the factors considered as being responsible for causing the illness, such as biological, genetic, or immunological. Psychological and emotional factors are also included under this dimension. Consequences refer to what kind of an effect the illness has had on the individual and include, in general, beliefs about quality of life and functional status. Identity refers to personal statements and labels the individuals have associated with an illness and is connected to symptom experience. The identity dimension also tends to be cumulative, and one symptom may influence

or compound another symptom, which can make the combined experience more intense. Timeline refers to the projected course of the illness. Chronic illnesses rarely have any cure and remain with the individual for their lifetime (Hagger & Orbell, 2003; Leventhal et al., 1984; Leventhal, Meyer, & Nerenz, 1980). The CSM is essentially a process of labeling or naming the illness experience and/or symptoms and, ultimately, considering for themselves how central these symptoms are to one's sense of self. The CSM is a model whereby people simultaneously take the cognitive and emotional representations of an illness and try to make sense of the illness (Leventhal et al., 1980).

The body of literature related to chronic illness experience, systemic scleroderma, and stigma supports the concepts found in Leventhal's CSM (Diefenbach & Leventhal, 1996). When confronted with a chronic disease, most individuals in the studies reviewed had created perceptions of their health conditions as a way of trying to make sense of and manage their chronic disease. Studies looking at the illness experience itself and how living with a chronic condition, including scleroderma, had affected them addressed the sense of loss and uncertainty, but also looked at ways in which individuals could achieve a good quality of life and find positive changes through benefit-finding.

Symbolic Interactionism

Symbolic interactionism will underpin this study (Blumer, 1969). Symbolic interactionism looks at interactions with others and the perceptions that shape the individual and the meaning behind these interactions. Although symbolic interaction is different for each individual, what connects people is their shared experiences with one another. There is a process that represents these shared experiences, as a sense of self is developed through the interactions with one another (Maz, 2013). Charmaz (2008) stated, "Individuals define and depict emergence

through drawing on shared meanings" (p. 157). The environment is shaped by the self and becomes part of the self (Grove, Burned, & Gray, 2013). How one views himself or herself is meaningful to one's self-concept and identity.

This study will focus on trying to understand the significant changes that take place with individuals living with systemic scleroderma and how this autoimmune disease affects self, self-concept, and identity. Grounded theory will help in understanding the social process of identity management for someone living with systemic scleroderma. Symbolic interactionism looks at interactions with others and the perceptions that shape the individual and the meaning behind these interactions. Although symbolic interaction is different for each individual, what connects people is their shared experiences with one another. There is a process that represents these shared experiences as a sense of self is developed through the interactions with one another (Maz, 2013).

The concept of symbolic interaction was originally founded by George Herbert Mead (1934); however, his student, Herbert Blumer (1969), actually developed the theory into what is known today as individuals forming meaning attached to objects, events, or phenomenon. Symbolic interaction theory has evolved over the years to take into consideration empathy developing capabilities (Aksan, Kisac, Aydin, & Demirbuken, 2009). Blumer identified three core principles for symbolic interactionism: meaning, language, and thinking. Meaning is the all-encompassing focus of symbolic interactionism, and language helps to provide this meaning for humans through symbols that can discern social relationships. Thinking can change the perception and interpretation for each individual who has attached a meaning to a symbol. If there is a universal meaning attached to a symbol, individual thinking can possibly change this universal meaning to meet individual needs (Aksan et al., 2009). One important criticism about

symbolic interactionism is that the theory really does not explicitly take into consideration emotions. Human beings have emotions, and these emotions add to one's individual and personal understanding of an experience. Symbols by themselves have no meaning unless a meaning is attached to them, and emotions can make this attachment even stronger (Aksan et al., 2009).

There are seven major assumptions of symbolic interactionism theory:

(a) people are unique because of their ability to use symbols;

(b) people become distinctly human through their interaction with others;

(c) people are conscious and self-reflective beings who actively shape their own behavior;

(d) people are purposeful creatures who act in and toward situations;

(e) human society consists of people engaging in symbolic interaction;

(f) the *social act* should be the fundamental unit of social psychological analysis; and

(g) to understand people's social acts, we need to use methods that enable us to discern the meanings they attribute to these acts (Blumer, 1969).

Synthesis of the Three Models and the Relationship to Scleroderma

Identity management can be adversely affected by a chronic condition, such as systemic scleroderma. How individuals begin to make sense of their chronic condition and create an understanding of what their chronic condition means personally to them is also important. Identity creates a sense of self-worth and purpose, where one belongs in the larger picture. This sense of self-worth comes attached to roles and social expectations. Self-concept and self-image also contribute to an individual's sense of self and identity. Living with a chronic condition may include a sense of loss, losing something that once was and no longer can be recovered. This loss of self is significant in people living with systemic scleroderma. The synthesis of these three

models focuses on the individual experience of living with systemic scleroderma. These three models help in understanding how an individual sees themselves, what meaning systemic scleroderma has for the individual, and how they are positioned in relation to others. Understanding how individuals make sense of what it means to be living with scleroderma and understanding what the social process is in identity management in people living with systemic scleroderma is important for advancing the science of scleroderma. By advancing the science of scleroderma, nurses will have a better understanding of this basic social process and will be able to better care for individuals with systemic scleroderma. Most importantly, as the disease progresses, nurses will be able to incorporate realistic interventions related to identity management in individuals with systemic scleroderma.

Summary

Systemic scleroderma is a destructive autoimmune connective tissue disease with debilitating and life-limiting physical and psychological effects. The phenomenon of identity management is the focus of this dissertation. The body of literature reviewed for this study included research on the chronic illness experience in general, the experience of living with systemic scleroderma, and how stigma can affect someone living with systemic scleroderma. Glaserian grounded theory methodology was used to understand the social process of identity management in individuals living with systemic scleroderma. The theoretical and philosophical perspectives supporting this study are social identity theory and role identity theory, the CSM, and symbolic interactionism.

Studies looking at the experience of living with a chronic illness address the concepts of biographical disruption, feelings of uncertainty, insecurity, and loss. Illness disruptions tend to challenge identity and force one to renegotiate envisioned plans (Burles & Thomas, 2012; Clarke

& Bennett, 2013; Flensner & Rudolfsson, 2016). Loss and uncertainty threaten the everyday predictable order, and eventually, loss becomes a reality that must be accepted (Lundman & Jansson, 2007). Being dependent on others was a concern that many individuals expressed, and becoming dependent on others contributed to a sense of loss autonomy and a sense of loss (Burstrom, Brannatrom, Boman & Strandberg, 2012; Chang, Tsao, & Huang, 2014; Cinar et al., 2013). The challenges of living with a chronic illness means that one begins to create new boundaries that help them cope and manage. Through this process of creating new boundaries, a deeper understanding of self and a cognitive mechanism by which one can find growth can emerge (Lindsay, MacGregor & Fry, 2014).

Individuals living with systemic scleroderma experience the same overarching concepts of biographical disruption, uncertainty, insecurity, and loss. Physical manifestations are the most frustrating, and facial disfigurement is, by far, the greatest sense of loss and can lead to stigmatization, social rejection, and isolation (Joachim & Acorn, 2003). Appearance, self-perception, roles, activity and quality of life, and sexuality can contribute to one's sense of identity, and a disruption or limitation to any of these elements can threaten one's identity (Oksel & Gunduzoglu, 2014).

Stigma occurs from within an individual based upon undesirable characteristics the individual is made aware of (Goffman, 1963). Stigma can either be felt or enacted, and in general, people who anticipate greater stigma tend to experience a lower quality of life. Both enacted and felt stigma can be devastating, but when enacted stigma reinforces felt stigma, the consequences could have a greater effect. The current body of literature related to stigma supports how both types of stigma are embedded in the experience of living with a chronic illness, such as systemic scleroderma. An individual's awareness of their physical and functional

limitations has an effect on their sense of self-worth (Berger et al., 2011). In order to avoid stigma, it is not uncommon for individuals with physical and functional limitations to not engage in social activities, and if they do need to socialize, make accommodations that do not appear to be out of the ordinary. Chronic illnesses that result in disfigurement have the highest reported levels of self-reported stigma (Berger et al., 2011; Brown, 2015; Lebel et al., 2013). Individuals with disfigurement state they sometimes feel they are flawed, ugly, and devalued. However, stigma can be overcome through various personal and social activities.

Benefit-finding can moderate the impact of felt stigma; however, this outcome is associated with overall wellbeing and not with continued physical distress (Lebel et al., 2013). Family, friends, and other means of social support can help to alleviate some of the stigma someone may be feeling and improve one's satisfaction with quality of life. Stress and social support can positively mediate the degree that someone can anticipate stigma (Earnshaw et al., 2011). The less stress an individual experiences, combined with a strong social support system, the less the degree of stigma an individual feels, the better they can cope with their chronic illness, and the better their quality of life experience.

Chapter III: Methodology

This study used Glaserian grounded theory methodology to answer the question: What is the social process of identity management in individuals living with systemic scleroderma? Glaserian grounded theory uses an inductive approach to understanding a social process and seeks to create a mid-range theory that is grounded in the data. A grounded theory is built upon the concepts discovered and the relationships that connect those concepts (Cooney, 2010; Glaser, 1992; Hernandez, 2010).

A Brief History of Grounded Theory

Grounded theory is a qualitative methodological approach first developed by Glaser and Strauss (1967). Grounded theory uses an inductive iterative approach and is unique in that this qualitative methodology concentrates on trying to understand the social process of a phenomenon and attempts to "describe, explain, and predict relationships between ideas that have been systematically selected and organized in an abstract representation of the phenomenon" (Maz, 2013, p. 453).

Grounded theory uses symbolic interactionism as its epistemological underpinning (Maz, 2013). Symbolic interactionism looks at interactions with others and the perceptions that shape the individual and the meaning behind these interactions. Although symbolic interaction is different for each individual, what connects people is their shared experiences with one another. There is a process that represents these shared experiences as a sense of self is developed through the interactions with one another.

Glaserian grounded theory is a methodology, whereby the work of data analysis is a constant comparative process (Glaser, 1965; Glaser & Strauss, 2008). Over the years, confusion and discourse developed when Strauss and Corbin collaborated, and critics were quick to point

out the differences and how the work of Glaser and Straus (1967) and the work of Corbin and Strauss (1990) were different and varied from the original methodology. When Charmaz (1995) introduced the method of constructivist grounded theory, this added to the debate, which continues among scholars and researchers to this day.

Rationale for Grounded Theory in Chronic Illness

Within the health sciences, including nursing, chronic illness is studied as a human experience in which there is a process associated with living with a chronic condition (Martin, 2007). This process is viewed as something that is deeply personal and a social phenomenon. Grounded theory is a qualitative research methodology that specifically looks at the social process of living with and working through an experience, for example chronic illness. The work of grounded theory provides several valuable strategies for examining the experience of chronic illness (Charmaz, 1990). People's experiences reflect their understanding and grounded theory will help to uncover this understanding (Charmaz, 1990). Grounded theory has also been previously used to uncover experiences related to other autoimmune diseases, for example lupus (Neville et al., 2014), rheumatoid arthritis (Bergsten, Bergman, Fridlund, & Arvidsson, 2011), human immunodeficiency virus (Poteat, German, & Kerrigan, 2013), and diabetes mellitus (Livingstone, Van De Mortel, & Taylor, 2011).

Methods

Sample: Theoretical Sampling and Theoretical Saturation

The type of sampling for this grounded theory study used purposeful theoretical sampling with potential snowball effect. Theoretical sampling is the "process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect" (Glaser & Strauss, 2008, p. 45). Theoretical sensitivity aligns closely with

theoretical sampling, and theoretical saturation in that sampling continues to develop as researcher collects and analyzes the data. What emerges from the data will guide and direct the researcher further in sampling. With grounded theory, the researcher is developing a theory, so the sampling process must fit the phenomenon under study. Participants were chosen based upon what was emerging from the data, in hopes to guide a richer data collection (Hernandez, 2010).

This study recruited participants who reported being diagnosed and under treatment for systemic scleroderma (diffuse scleroderma), because individuals who were living with systemic scleroderma would allow the grounded theory to capture aspects of the disease that involve more rapid progression and symptom intensity than within individuals living with limited scleroderma. The inclusion criteria for this study were: (a) self identifies as a woman, (b) reports a diagnosis of systemic scleroderma for at least one year, (c) understands and speaks English, and (d) 18 years of age or older. To secure a sample that could allow for a wide breadth of trajectory and clinical manifestations, using theoretical sampling, eight participants were recruited who had been living with systemic scleroderma for one to eight years, and eight participants were recruited who had been living with systemic scleroderma for nine to 14 years. A sample size of 16 participants was recruited; however, due to a loss of follow up, a total of 15 participants were recruited and allowed the grounded theory to achieve theoretical saturation.

Recruitment

A recruitment announcement was distributed at the rheumatology clinic at the Froedtert and Medical College of Wisconsin medical clinic, where patients with scleroderma are commonly seen. An announcement was also posted to the Scleroderma Foundation-Greater Chicago Chapter Facebook page, inviting individuals to respond through a private email if they were interested in participating in this study. Information about this study was also distributed to

the local scleroderma support network, which is part of the Froedtert and Medical College of Wisconsin rheumatology clinic in Milwaukee. Initial recruitment did not result in sufficient numbers of interested participants, so an amendment was approved to change the study protocol to allow for either in-person interviews or interviews by phone. After connecting with the National Scleroderma Foundation, 73 individuals immediately expressed interest in the study, which allowed for robust theoretical sampling and geographical representation of participants having characteristics needed to achieve the collection of a variety of illness experiences of systemic scleroderma. Interested participants were contacted and screened for meeting inclusion criteria, and based upon the screening, participants were selected by the researcher for interviews. Examples of characteristics used in theoretical sampling included time since diagnosis, employment status, relationship status which included if participants had children, and if participants had any comorbidities not related to systemic scleroderma.

Data Collection Procedure

After a participant expressed interest in the study, a time was determined to conduct the interview by phone or in person. Consent was reviewed and signed (in person) or verbalized (by phone) before data collection began. Data collection consisted of a semi-structured interview composed of questions to address identity and how someone begins to manage their identity with the progression of systemic scleroderma. The semi-structured interview, by its very nature, had the flexibility to include questions driven by the information the participant provided. Participants were also asked to complete a demographics questionnaire and the Modified Rodnan Score tool prior to the interview (Rodnan, Lipinski, & Luksick, 1979).

Data Collection

All interviews were digitally recorded. Interviews were deidentified when transcribed into a Microsoft Word document. All data were protected by keeping the written transcripts locked in a file cabinet or by a password (digital) protected login.

Measures

Descriptive demographic data included age, gender, marital status, number of children, employment status, and how many years they have been living with systemic scleroderma (see Appendix A). A semi-structured interview captured the individual experience of living with systemic scleroderma and the process of identity management associated with systemic scleroderma (see Appendix B and Appendix C). The semi-structured interview schedule went through a revision partway through data collection to facilitate advancement of the data analysis by asking more probing questions that was indicated by simultaneously interviewing, transcribing, and analyzing the data. An Institutional Review Board (IRB) amendment was submitted to obtain approval for the changed interview schedule at the point in the analysis when it became clear that additional questions needed to be added.

Rodnan score. The Modified Rodnan Score tool (see Appendix D and publicly available) assessed each participant's level of skin sclerosis involvement on the body. Scores can range from 0 to 51, with a higher number indicating more severe illness (Rodnan et al., 1979).

Human Subjects Protection

Approval to conduct the study was obtained by the UW-Milwaukee IRB (approval number 18.285), with a minimal risk designation (see Appendix E). Consent was reviewed and signed with participants before data collection began. Participants were assigned pseudonyms to protect confidentiality. All data were securely filed and protected by either a password (digital) or by a lock and key (paper).

Data Analysis

Data analysis was completed following Glaserian grounded theory methods (Glaser, 1992), which included open coding, selective coding, theoretical coding, memoing, and field notes. An iterative, constant comparative process was used to identify similarities and differences emerging from the data which allowed the researcher to develop core categories and achieve theoretical sampling. A middle-range grounded theory was developed describing the basic social process of identity management in individuals living with systemic scleroderma.

Open Coding

Open coding was the initial step after data collection. The researcher took words and phrases and attempted to understand what those words and phrases implied by looking at what was similar and different. Open coding took place line-by-line from the transcript, and codes were recorded in the margin. Open coding also included looking at memos and field notes. Throughout the initial phase of open coding, the researcher is trying to find concepts and sociological constructs that presumably identify an active process related to incident and behavior (Glaser, 1992; Hernandez, 2010).

Included as part of open coding is what Glaser (1992) called in vivo coding. In vivo coding refers to a type of coding whereby the researcher identifies important words and language uniquely used by the participant. In vivo codes emerge from the language spoken within the transcript (Glaser, 1992; Hernandez, 2010). These in vivo codes are significant because they help to make clear on a personal level how and what the individual is possibly doing to solve a problem and reveals this in a unique and descriptive fashion. Open coding is a long and arduous process and continues until the researcher begins to see a core category emerge. Once this core category becomes somewhat clear, it helps the researcher begin to see an overall general pattern

that might represent the behavior that is consistently being used to solve a problem (Glaser, 1992; Hernandez, 2010). This process continued by using all data obtained in the interviews.

Selective Coding

Selective coding was the next step in data analysis. This intermediate phase continued using the continuous comparative method; however, now the emphasis was on developing more abstract categories. Selective coding was achieved by taking only the concepts from the initial phase and relating them to the core categories. This analysis continued until theoretical saturation was achieved. Theoretical saturation means there are no additional data found and that similar situations are seen consistently in the analysis (Glaser & Strauss, 2008).

Theoretical Coding

Theoretical coding was the final step in data analysis, whereby the conceptual model was constructed based upon the relationships discovered through the core categories (Hernandez, 2010). Through the process of theoretical coding, the basic social process was beginning to emerge.

Memoing

Memoing was an important step in the data analysis process. Memoing became part of the theoretical coding process and, ultimately, part of the theory itself. Every memo had a date, time, and heading. Memoing represented the researcher's thoughts during all steps of the analysis and was a continuous ongoing process. Memoing is free expression in written form of what the researcher is thinking about related to coding, behavior, and relationships, and there is no right or wrong way to do memoing. All memos were organized in a way that corresponded to each transcript and coding step, which made it easier to see the thought process and analysis throughout the entire grounded theory process.

Diagraming Concepts into a Middle-Range Theory

Diagraming has the benefit of providing a visual representation of the categories created and the relationships between categories; diagrams are a visual conceptualization (Charmaz, 2014; Corbin & Strauss, 2008). Initial diagrams are the beginning work and take on many different styles; however, as this researcher continued to think about the process uncovered, the diagrams evolved through several iterations. A middle-range theory should be parsimonious. Parsimony refers to being able to explain a theory in as few concepts as possible in order to explain the meaning of the theory. The challenging part of developing this middle-range theory was having the temptation to use all of the categories (Fawcett & Garity, 2009). Categories needed to be synthesized in order to identify both the core categories and subcategories.

When developing a grounded theory, the purpose is to create a theory that explains a pattern of behavior that has become problematic and challenging (Glaser & Holton, 2004). Glaserian grounded theory tries to uncover a basic social process through a core category (Glaser & Holton, 2004). This core category becomes the center of the theory, or the theme that names the process and summarizes all variation in behavior (Glaser & Holton, 2004). Once the core category is centered, the rest of the integrating related categories can support the theory and are positioned around the core category to reveal a sequence. Ultimately, the final diagram represents a basic social process and is said to now have theoretical completeness (Glaser & Holton, 2004).

Constant Comparative Method

The constant comparative method keeps the researcher close to the data and allows for discovery. The constant comparative method allows the researcher to be creative and flexible in order to develop a mid-range theory. The constant comparative method is the simultaneous

process of collecting data, coding the data, analyzing the data, and memoing (Glaser & Strauss, 2008; Hernandez, 2010). Coding all of the data first does not allow the researcher to begin to see emerging patterns that spawn further questions. Using the constant comparative method maintains the authentic purpose of theoretical sampling. Theoretical saturation is when no additional data are being found for which new categories can be created, and theoretical insights are not emerging (Glaser & Strauss, 2008). Through the constant comparative method and theoretical sampling, theoretical saturation was achieved.

Maintaining Rigor, Trustworthiness, and Quality

In qualitative research, scientific rigor is illustrated by adherence to the chosen research methodology and how the researcher has employed that methodology during analysis. Scientific rigor for qualitative research is also demonstrated through conscientiousness and dedication to the philosophical perspective and underpinnings of the method; thoroughness in data collection; usage of all data, not just selected chosen pieces in the analysis process; and most importantly, an understanding of self. Having self-understanding is important because "qualitative research is an interactive process shaped by the researcher's personal history, biography, gender, social class, race, ethnicity, and by the study participants" (Grove et al., 2013, p. 58). Fundamentally, scientific rigor for grounded theory is strengthened when the method is applied properly, and all details related to grounded theory have been used.

Apart from adherence to the methods of grounded theory, four criteria were applied to this study to demonstrate trustworthiness and integrity. The four criteria follow the work of Lincoln and Guba (1985), which is considered to be the gold standard for establishing rigor. The four criteria include credibility, transferability, dependability, and confirmability. When a researcher does not establish rigor in a way that is acceptable within the discipline, that

researcher risks losing trustworthiness and integrity within the discipline from his or her peers. Dependability and confirmability lead to credibility, which leads to transferability (Petty, Thomson, & Stew, 2012).

Differing epistemological assumptions underlie each of the various qualitative methods researchers can use to study their phenomena (Koch & Harrington, 1998), and "goodness criteria are themselves rooted in the assumptions of the paradigm for which they are designed" (Guba & Lincoln, 1989, p. 236). Quantitative researchers approach their work from a positivist perspective, where internal and external validity and reliability are seen as establishing rigor. However, these same procedures and criteria cannot be applied meaningfully to qualitative research (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Quantitative researchers need to generalize their findings to the general population, ontologically and epistemologically qualitative researchers cannot. Change within a phenomenon is expected and can represent growth within the human condition. There is no tolerance for this within a positivist, objective view (Guba & Lincoln, 1989).

Credibility

Qualitative researchers do not make an effort to control variables. Qualitative research pursues the need to explore the whole and the complexity that surrounds the whole (Petty et al., 2012). Credibility refers to the degree to which the findings can be trusted or believed by the participants who were in the study—how well do the findings fit the experiences of the participants (Lincoln & Guba, 1985; Petty et al., 2012). The strategies used to strengthen credibility include: (a) prolonged engagement and persistent observation, whereby the researcher can appreciate a deeper understanding of the phenomenon under study, and (b) peer debriefing, which allows the researcher to bring findings and conclusions to peers who are removed from the

study in order to elicit new insights and ideas. Peer debriefing was accomplished through the collaboration of this researcher's major professor.

Collecting supporting data and member checking are two additional strategies researchers can use to strengthen credibility (Lincoln & Guba, 1985; Petty et al., 2012). Member checking was used in this study as a means to confirm accuracy and credibility. Participants in this study represented a cross-sectional picture of individuals living with systemic scleroderma. Findings from the first group of participants, who had systemic scleroderma for one to eight years, were shared and incorporated into the semi-structured interview conducted with the second group of participants, who had systemic scleroderma for greater than eight years.

Transferability

Given the epistemological underpinnings of the various qualitative methods, it is the context in which the findings emerge that is important and, thus, cannot be generalized to the greater population. Transferability, or sometimes called applicability, is the extent to which the findings can be applied in other contexts or possibly with other participants (Lincoln & Guba, 1985; Petty et al., 2012) and is evaluated by the reader. Purposive sampling allowed for transferability by collecting a variety of perspectives related to the phenomenon under investigation, which simultaneously led to rich, thick, descriptive data (Lincoln & Guba, 1985).

Dependability

Quantitative studies should be replicable in order to demonstrate reliability and validity. Qualitative researchers do not have this capability for the simple reason that the same experience can vary between people and time. While doing grounded theory, data analysis can be powerful. Insight can emerge anywhere throughout the analysis. Dependability is being able to produce an audit trail of your data and findings (Lincoln & Guba, 1985). An audit trail was obtained and

consisted of all recordings and transcribed interviews. The audit also included all field notes and memos, as well as coding and analyses.

Confirmability

Confirmability is making sure the data and the interpretations are rooted in the context of the participants' experiences and not reflective of the researcher's bias (Lincoln & Guba, 1985). The findings must be rooted in the data. Confirmability and dependability can both be accomplished simultaneously, whereby all participants' recordings, transcripts, memos, and field notes will be available. A confirmability audit was completed by a fellow doctoral student with familiarity with grounded theory. The confirmability audit included an entire audit trail, meaning that each concept from the final grounded theory was traced through the analysis and decision-making process to the raw data and that select raw data was also traced to the point where it emerged in the model or was discarded. The auditor agreed and provided written evidence that there was agreement with the data analysis process.

Summary

Glaserian grounded theory was the methodological approach used to uncover the basic social process of identity management in people living with systemic scleroderma. Theoretical sampling was used to collect data focusing on the overarching question of who participants were before being diagnosed with systemic scleroderma. This researcher used constant comparative methodology, which led to theoretical saturation in data analysis and used Glaserian grounded theory to perform open coding, selective coding, and theoretical coding. Maintaining rigor, trustworthiness, and quality was considered by the criteria established by Lincoln & Guba (1985), which include credibility, transferability, dependability, and confirmability. Ethical considerations included obtaining IRB approval from the University of Wisconsin-Milwaukee.

Chapter IV: Results

Chapter IV presents the findings of 15 interviews from women living with systemic scleroderma. The purpose of this study was to develop a grounded theory explaining the process of identity management in women living with systemic scleroderma. The research questions driving this study were:

1. How does the identity of people with systemic scleroderma change over time?
2. How does the onset and progression of systemic scleroderma affect roles and self-concept?

The first section of this chapter will discuss the characteristics of the 15 women who participated in this study. The second section of this chapter will explain the grounded theory process as it relates to identity management in women living with systemic scleroderma.

Participant Characteristics

Fifteen women participated in this study, with an age range between 34 and 69 years (Mean = 52, Median = 54, SD = 10.4) (see Table 1). The number of years living with systemic scleroderma ranged between one and 15 (Mean = 7, Median = 7, SD = 4.77). Forty percent of the participants reported working full-time and 20 percent were not currently working due to disability. Sixty percent of participants were married and twenty percent were divorced. Sixty percent of participants had children. All participants were asked to provide a self-report of the Modified Rodnan Skin Score prior to being interviewed. The range of the Modified Rodnan Skin Score was between 2 and 43 (Mean = 16.3, Median = 12, SD = 10.83).

Table 1

Demographics (n = 15)

Category	Percent (n)
Work full-time	40 (6)
Work part-time	13.3 (2)
Not working (disability)	20 (3)
Not working	13.3 (2)
Retired	6.6 (1)
Volunteering	6.6 (1)
Married	60 (9)
Single	13.3 (2)
Divorced	20 (3)
Widowed	6.6 (1)
Children	60 (9)
No children	40 (6)

Participant Interviews

Participant 101 (Rachel)

Rachel is a 54-year-old female who has been living with systemic scleroderma for three years. She has been married for 14 years and has no children. She currently works full-time as a supervisor and still drives her own car. She started noticing that her fingers were turning white on a regular basis and knew that this was not normal. She eventually noticed that her fingers were curling up and becoming stiff. She stated that her symptoms began several years prior to being diagnosed. Rachel made an appointment with her primary physician, who she felt was not adequately relieving her symptoms. Eventually, she was referred to a rheumatologist and was diagnosed October of 2015. At the time of the interview, Rachel stated that her joints do feel stiff at times, and this is making it difficult for her to walk at times without pain. There were ulcerations noted on her fingers bilaterally near the interphalangeal joints. There were creases or lines evident around the corners of her mouth; however, she had no difficulty opening her mouth and speaking clearly.

Participant 102 (Heather)

Heather is a 42-year-old female who has been living with systemic scleroderma for three years. Heather is single and lives with a male partner. She has no children. Heather works full-time as a software consultant. Heather's hobby is working on old cars and driving as a sport. She enjoys working with her hands, and when this became difficult to do, she reached out to her primary physician. Her symptoms began with her hands hurting to the point that she could not use them the way she always could. Heather found it difficult to grab things, and she could not make a fist. Initially, her physician thought that her symptoms might be a result of carpel tunnel. She was prescribed some pain medication and sent home. Several months had past and her symptoms were not improving, in fact, they were getting worse. Heather knew that there was something more serious going on than carpel tunnel. Heather went back to her primary physician, who referred her to a rheumatologist. Heather was diagnosed with systemic scleroderma in February 2015. Her fingers were beginning to show contractures, but no open ulcerations were noted. She has no difficulty ambulating.

Participant 103 (Carolyn)

Carolyn is a 38-year-old female who has been living with systemic scleroderma for four years. She is newly married and currently has no children. Carolyn is working full-time as a pastoral minister and finds this work meaningful, especially now. Carolyn has extensive internal organ involvement. The symptoms began in her fingers; however, the most severe symptom began in her lungs. She was diagnosed with interstitial lung disease related to systemic scleroderma and used portable oxygen when needed, but is finding that she needs to be on oxygen more regularly now. She is finding it difficult to walk and perform every day activities. Much of what she was able to do, she cannot anymore. She is grateful that she recently married a

very understanding man. Carolyn talked a lot about the support system that she has and how this has helped her tremendously cope with systemic scleroderma and the sudden changes this disease has handed her.

Participant 104 (Janet)

Janet is 60-year-old female who has been living with systemic scleroderma for three years. She has been married for 16 years and has no children. Janet did not indicate that she is retired, she just stated that she was not working. For most of her life, she has been living an active, healthy lifestyle. Recently Janet had been experiencing several health issues for which she had sought medical attention. Janet had several treatments, which included thyroid surgery. She continued to feel terrible and continued to experience major health issues, so she decided to go to the Mayo Clinic for a complete checkup. During this medical checkup, Janet discovered she had systemic scleroderma. Janet was diagnosed with systemic scleroderma in 2016. Janet does have some difficulty walking up the stairs, but she stated that although she has needed to make some changes in her life, scleroderma has not been severe enough for her to make significant changes yet.

Participant 105 (Debra)

Debra is a 35-year-old female who is newly diagnosed with systemic scleroderma. She stated that she has been living with systemic scleroderma for about one year. Debra has been married for 14 years and has two children. Debra works part-time due to the effects of scleroderma, and she works as an administrative assistant from her home. Debra journaled all of her symptoms and experiences, and she believes that this is what helped her in being properly diagnosed early. Night sweats were the earliest symptom, followed by colds that were difficult to fight off. Symptoms began to appear more recently on her hands and arms. Debra noticed blisters

on her fingers and then red marks on her arms. Eventually, Debra noticed her hands turning purple and feeling stiff and her joints began to hurt. Debra also began experiencing serious heartburn. Debra stated on several occasions that this disease has taken away her dignity.

Participant 106 (Samantha)

Samantha is a 58-year-old female who has been living with systemic scleroderma for four years. Samantha is widowed, but states that she had been married for 30 years. She has three children. She continues to work full-time as a receptionist at a law firm. Originally from England, she has lived in the United States for many years. Samantha believes that the stress of losing her husband and eventually losing her house led to the onset of scleroderma. She described how her first experience with symptoms began with her hands and then moved to other parts of her body. She could not get up from the chair, she could not dress herself. Samantha stated that she could not open her mouth wide enough to eat and that her condition was progressively getting worse. Her rheumatologist did not know what was going on, so he referred Samantha to a specialist in Los Angeles, where she finally was given the diagnosis of systemic scleroderma.

Participant 107 (Catherine)

Catherine is a 51-year-old female who has been living with systemic scleroderma for five years. Catherine has been married for 30 years and has three children. She works full-time as a secretary at a resident care center. Catherine stated that she was a stay-at-home mom and that she started working full-time in 2010. Her initial symptoms began with her hands and fingers. Her fingers were swelling and becoming stiff. When Catherine's fingers began turning purple, this is when she knew that something was seriously wrong. Catherine went to her primary physician,

who was not sure exactly what was going on for a healthy 47-year-old. She was referred to a rheumatologist, who diagnosed her with systemic scleroderma.

Participant 108 (Nicole)

Nicole is a 45-year-old female who has been living with systemic scleroderma for seven years. Nicole stated that she has been married for two years and that this is her second marriage. She has two children, one biologic and one stepson. Nicole currently works full-time as a payroll professional, but she is currently on medical leave. Nicole indicated that her symptoms began with her hands swelling and hurting, and she could not understand why this was happening and why these symptoms were not going away. Her fingers and toes were turning purple and then white, and this had never happened before. Nicole also noticed that the skin on her fingers was being stretched tight and that she had a difficult time closing her hands. Nicole went to her primary physician and was told that her symptoms were a result of a condition called Raynaud's phenomenon. Nicole was referred to a rheumatologist, and after some further tests, she was diagnosed with systemic scleroderma.

Participant 201 (Ruth)

Ruth is a 56-year-old female who has been living with systemic scleroderma for 14 years. Ruth is divorced and has two children. She has been disabled since 2010. She said that her symptoms came on fast, which concerned her a great deal. Ruth's symptoms began with swollen, puffy hands, which quickly advanced to cold fingers that turned purple. Ruth immediately made an appointment with her physician, who said that her symptoms could be several things. After several tests, her physician referred her to a rheumatologist. As the disease progressed, Ruth eventually needed to move in with her son, and she expressed that she has a lot of support. Ruth lives upstairs in a large room that has been converted into a living space with a bathroom. She

has a chair lift attached to the stairs so she can ride up and down the stairs. She has several assistive devices that help her function throughout the day, including a walker, cane, and mechanical bed.

Participant 202 (Brenda)

Brenda is a 60-year-old female who has been living with systemic scleroderma for 10 years. She is divorced and has no children. She is currently retired and volunteers in the community and facilitates her own support group for people with scleroderma. When Brenda started noticing some symptoms, she went to her physician. Her physician indicated that what she was experiencing might just be a virus and she should wait. Eventually, everything on her body began to hurt and she had difficulty walking and breathing with activity. Brenda went back to her physician, and after testing, she was diagnosed with scleroderma and referred to a rheumatologist. Most of Brenda's disease progression is internal and has primarily affected her gastrointestinal system. She also has minor pulmonary issues. Brenda does not have tight skin on her face; however, her fingers and hands are red and slightly swollen. Frequently throughout the interview, Brenda focused on how her support system had been missing and how many of her friends have distanced themselves from her and hurt her. She stated that her own support group for scleroderma has helped her.

Participant 203 (Cynthia)

Cynthia is a 69-year-old female who has been living with systemic scleroderma for 10 years. Cynthia has been married for 44 years and has two children. She is retired and volunteers in the community. She also facilitates her own scleroderma support group. Scleroderma has primarily affected her internal organs, with little skin involvement. She has complications related to her gastrointestinal system and she also has some shortness of breath. Cynthia was concerned

that someday she might be dependent upon oxygen. Cynthia remembers that her earliest symptom was being short of breath after going on normal walks. Cynthia also began noticing that she was having difficulty eating and drinking, she would choke and cough. She went to her physician, had several tests and procedure done, and was diagnosed with early stage pulmonary hypertension. Cynthia eventually had an appointment with a rheumatologist, which is when she was officially diagnosed with systemic scleroderma.

Participant 204 (Rebecca)

Rebecca is a 39-year-old female who has been living with systemic scleroderma for 14 years. This is her second marriage and she has been married for five years. She has two children, with her youngest being 18 months old. Rebecca is currently working part-time as an elementary substitute teacher. Rebecca explained that her first symptom related to scleroderma was joint pain and that she hurt constantly. The pain was persistent and did not get better over time. She noticed that her feet were swollen and that she could not wear shoes. This is when Rebecca knew something was not right. Rebecca went to her primary physician and was told that she was probably dehydrated and that she needed to drink more liquids. She was sent home, but the joint pain was still so intense. There were many nights she cried herself to sleep. Rebecca went back to the doctor and was prescribed an antidepressant. Several days after being on the antidepressant, she said that she felt like a zombie and that her body still hurt all over. Rebecca went back to her doctor again and was told that all tests came back negative and there was nothing more to do. Rebecca raised her hands to her eyes to wipe away the tears and then lowered them again, and the doctor noticed that her fingers were turning purple. The doctor told Rebecca that what she had was Raynaud's phenomenon, and she was immediately referred to a rheumatologist. Rebecca was finally diagnosed with systemic scleroderma. Rebecca also

explained that she almost lost her baby because of scleroderma. During her pregnancy, she was in so much pain that she discussed with her obstetrician that she just could not go through with this pregnancy anymore. Rebecca decided to deliver her baby prematurely because scleroderma was not allowing her uterus to stretch anymore. Despite everything that has happened, she said that she keeps forcing herself to smile. Rebecca said that she is living with intention and all she has is this day. Her 18-month-old son keeps her focused in the moment.

Participant 205 (Melissa)

Melissa is a 57-year-old female who has been living with systemic scleroderma for nine years. Melissa is divorced and has two children. She is currently not working; however, she did work as an IT director and manager. She also volunteers in her community. Melissa explained that she was diagnosed with a pulmonary disease before officially being diagnosed with systemic scleroderma. About four months later, she then developed Raynaud's phenomenon. She saw several physicians trying to get answers. Eventually, there were several rheumatologists working with her. Melissa expressed how scary the experience was because she was just diagnosed with a rare lung disease, and within a short period of time, she was diagnosed with another rare disease. Melissa's symptoms also included very itchy inflamed skin, a persistent cough, and gastrointestinal reflux. She eventually began feeling fatigued and drained of energy. She also noticed that she was now becoming more short of breath when she would walk. Melissa went back to her physician and told him that something was not right. Her physician did not take her concerns seriously and indicated to her that she needed to lose weight and that she would feel better. Melissa felt ignored and devalued and explained that she just pushed through until she finally had a diagnosis of scleroderma. Melissa explained that her main concern through all of this was reassuring herself and her family that she would be all right. She expressed how

frustrated she is that she cannot pick up simple items and that she feels like she is trapped inside of an 80-year-old woman.

Participant 207 (Angela)

Angela is a 65-year-old female who has been living with systemic scleroderma for 15 years. She has been married for 45 years and has four children. She reports being disabled since 2006. Angela struggled with symptoms for almost a year. Her family had encouraged her to go see her doctor, and eventually, she went to see a rheumatologist. After several tests, Angela was finally given a diagnosis of systemic scleroderma. Angela described how frustrating and disappointing it was to feel the way that she did and not have a name for how she was feeling. Her initial symptoms began with the skin on her face tightening up. The skin around her mouth was getting so tight that it became difficult for her to open her mouth. Angela then began to notice pigment changes on her chest and upper arms. She feels that she had been living with scleroderma for several years before being diagnosed and getting on a treatment regimen. Angela expressed how difficult it was to adjust to what she is doing now. She can still drive, but her daily activities need to be spaced out. Angela explained that she has a strong faith and relationship with God and that her faith is a good sense of support for her. Angela explained that she discovered that she needed to pull out of herself what she did not know she had in her.

Participant 208 (Jessica)

Jessica is a 51-year-old female who has been living with systemic scleroderma for 13 years. She is single, has no children, works as a computer analyst, and has a master's degree in Theology. Her symptoms began with a bad cough that eventually led her to see her primary physician. She was placed on inhalers for asthma. Her cough persisted, and Jessica went back to her doctor for a follow up visit. She followed through with several tests to rule out pneumonia

and was placed on oral steroids. Her sister noticed that the only time that Jessica coughed was when she was eating or drinking. The following week Jessica was seen by a rheumatologist and discovered that she had esophageal dysfunction and not a lung condition. She was relieved to finally have a diagnosis and name for what she had. Jessica was losing weight, and she was feeling frustrated because she could not work nor did she have the energy to function normally daily. She struggled to get out of bed and found herself becoming very depressed. Jessica journaled daily about her experience living with systemic scleroderma, and this journaling has been therapeutic.

Explication of the Grounded Theory

Reclaiming self was the basic social process that emerged from this grounded theory and can be defined as getting back something that has been taken away from you (https://dictionary.cambridge.org). Reclaiming self is a process that takes place over time and drives an individual to look deeper into one's inner core values and beliefs. This study revealed that there is both an outer self and an inner self. Before scleroderma, the outer and inner self are woven together to create one's identity and sense of self. As someone lives with the aggressive consequences of systemic scleroderma, both the outer and inner self can be disrupted, or torn apart. However, one's inner core values and beliefs remain constant or stable, and this inner core self is what is nurtured to reclaim a sense of self. Reclaiming, in various forms, was the concept that permeated throughout the many stages of living with systemic scleroderma. All the participants in this study were trying to hold on to or protect their identity in one way or another. The younger the participant was, the more insistent she was at trying to reclaim her identity. Heather explained,

> I still think that I am a strong enough person. If I find ways to do it myself, if I find ways to overcome something, I'll do it. So, I would say that's in my personality.…I'm not going to let things stop me.

Four core categories emerged from this grounded theory (see Figure 1). *Adapting to changes* are the behaviors that participants with scleroderma went through in order to carry on with their everyday lives. Behaviors included paying attention to how they were physically feeling and purposely making accommodations. These accommodations involved changes in their personal and family life, as well as work or professional life. *Dismantling of self* was an internal process, where participants with systemic scleroderma lost their sense of self and purpose. Their internal and external world was crumbling right in front of them and they felt helpless, lost, and destroyed. *Reclaiming self* was a deep internal reflective process, which included letting go and reevaluating, which led to reclaiming self. There was a sense of accepting what is and letting go of what was. Finding a greater purpose in life and understanding that having systemic scleroderma had a reciprocal principle was enlightening. *Embracing self* was also a deep reflective process. This self-reflection built determination and gave participants with scleroderma permission to live their lives on their own terms. Embracing self was not about accepting what *is*, rather it was a way to reclaim a perceived lost identity by realizing that who you are deep inside has not changed. This internal reflective process revealed that their core identity was never lost, and this allowed them to live with intention. Embracing self allowed participants to rewrite and rebuild their biographies. Having systemic scleroderma not only helped themselves, it also was helping others.

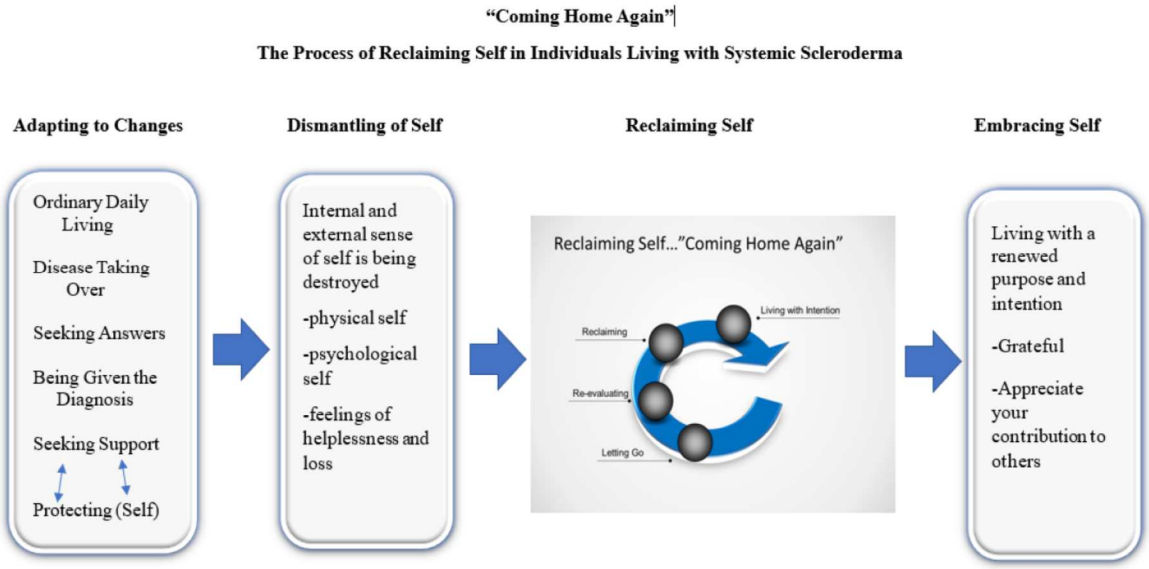


Figure 1. "Coming home again."

Reclaiming Self in the Process of Losing Self

Adapting to Changes

For individuals living with systemic scleroderma, adjusting to the many changes taking place in their body and in their life was challenging. Many of the changes focused on how they needed to limit activity and deal with physical limitations and on the overall decreased quality of life. Learning to listen to their body and coming to terms with how they were changing were important factors to master, as explained by Rebecca,

> So, I guess that was like the first night and then I started counting stairs and realized that after stair number 7, I had to take a break. But it took forever just to get inside the apartment to the point where I had to request a downstairs apartment…I count every step.

For participants who had more internal involvement, it was more difficult for people to understand why they did not have the stamina to keep going. They felt as if judgments were being made towards them. Melissa noted, "People judge that you have a broken leg or that you have Down's syndrome, and people can see that you look different, but if it's in the inside…they don't understand."

Participants who had children at home found it difficult to explain what was going on with mom and why she looked different or could not even smile easily anymore. Jessica described, “It was very painful to hear [questions from my niece and nephew]and try and explain to a 9- or 10-year-old that I can’t smile anymore. They didn’t understand it.” Part of adapting is beginning to accept the fact that you are not the same and that you cannot do the simple things anymore, as noted by Ruth, “I still wanted to work. I was working three jobs at the time and …still wanting to do the things I was doing, but not able to.”

Dismantling of Self

Participants expressed how living with systemic scleroderma had taken pieces of themselves away from them that they will never get back. Dismantling of self is how many of them felt as they saw their bodies and life changing right before their eyes. For many of the participants, this change was happening before it was supposed to happen. They were losing parts of themselves that they will never get back. Systemic scleroderma stole their life and identity. Many felt like they lost the opportunity to have the life that other people their age would have. Jessica described how losing her identity was a major part of living with systemic scleroderma, “Losing one’s identity was such a big thing to the disease. It’s the emotional toll that I took when all of this happened…I lost identity. I lost who I was.” Jessica noted, “Initially, scleroderma took away every part of my identity.”

Participants explained that their feelings of loss of self grew from feeling useless and helpless. They felt like they were losing their purpose. Many discussed their diminishing roles and the difficulty of being present with their spouse, children, and friends. Since there is no cure for systemic scleroderma, some described themselves as feeling betrayed and trapped by the disease and that there was nothing they could do about it. Catherine recounted, “I think I cried a

lot when nobody was home at first, and then I just acted like it wasn't fair." Physical changes, especially to the face, contributed greatly to their loss of identity and loss of self. Looking in the mirror and not recognizing who you are was upsetting, and for some, disturbing, as conveyed by Rebecca,

> I have a different face. And for years I was…I don't know her. I look in the mirror and I don't know her. My nose is different, my lips, my cheekbones.…When I look in the mirror, I don't see me or the person I love.…it's not the face I grew up with.

Debra further explained, "It's just, you know, ironic that somebody that has been complimented their whole life on how perfect their skin is…to now have this condition that is changing it so quickly."

Reclaiming Self – "Coming Home Again"

Reclaiming self required participants to reach deep inside their inner self to recognize that who they really are had not changed. One participant described this sense of reclaiming self as if she were coming home again. She recovered what she thought she had lost.

Participants began to move away from their external identity and external purpose, which primarily consisted of how they carried out roles and what they did on a daily basis, and focus on who they are as a person inside. Participants realized that their inner self is what remained stable. This inner self revealed their real purpose in life and how grateful they are able to still appreciate the little things that give them purpose. Cynthia stated, "I am so grateful and think how lucky I am…and I'm one of the older ones."

Understanding that systemic scleroderma does not have them, but rather, they are an individual who is living with systemic scleroderma brought about an enlightenment that having scleroderma was a way to help others. Angela expressed, "I may have this [systemic scleroderma], but it doesn't have me!" Jessica expressed, "I no longer define myself by what I

do. I had to figure out who I was inside…. it's defining who I am inside, how I share my gifrts and shar myself with others."

Most participants expressed that having systemic scleroderma was actually something positive in their life. Having systemic scleroderma helped them to be grateful and to appreciate the little things in life. Living with systemic scleroderma helped them find new meaning and purpose in life. Having systemic scleroderma helped many participants discover who they really were prior to systemic scleroderma, explained by Jessica, "I think I found I didn't really know who I was prior to scleroderma." This new meaning and purpose arose from their inner self, which allowed them to see that their inner self helped them to reclaim what they thought they had lost—identity. Having systemic scleroderma allows one to live in the moment with intention. Samantha described, "This [systemic scleroderma] made me realize how important life is. It's made me realize how precious life is and that nothing else matters."

One participant was still struggling to find anything positive with having scleroderma. Living with scleroderma had changed everything in her life. Her primary focus was trying to protect her role of being a mother to her children. She indicated that she would endure the pain in order to be a mother, and she would do everything to cover up the physical changes taking place so her children would not notice. Catherine spoke of how she would take pictures of herself and keep them in order to hold on to the memories of who she was, "I have pictures on my phone so I can compare before and after."

Reclaiming self is a process in itself that takes place. Participants needed to "let go" of what they were trying to still cling to. Once they allowed themselves to let go, then they were free to reevaluate who they are. This reevaluation meant searching inward and finding their inner

self. Once they discovered their inner self, this led to participants being able to reclaim self, or reclaim their identity.

Embracing Self

Participants discussed how accepting the changes that are taking place in their life helps to embrace the changes. Accepting takes time and is an internal process. Embracing self is understanding and coming to terms with limitations and not feeling like you must justify what you cannot do anymore. Adapting to your environment, adapting to new roles, and accepting that you are dependent on others is part of embracing who you now are. Through the process of reclaiming self, one discovers how to embrace self. Embracing self allows someone who is living with systemic scleroderma to live with intention and a new purpose, as explained by Ruth,

> I don't really internalize them [feelings] too much. I'm not mortified by it or I don't really feel ashamed about it. It's what I got.… I want to make a more positive role in what I can do for others… I want to be there for the next person.

Six subcategories emerged from the core category of adapting to changes that helped to explain the process of how participants adjusted to the onset and progression of living with scleroderma. The six subcategories help to explain the actions involved in adapting to scleroderma. *Ordinary daily living* describes how participants expressed their lives prior to experiencing symptoms and being diagnosed with systemic scleroderma. All participants described themselves as being independent and self-sufficient. Ordinary daily living included being fully involved and having a full life. *Disease taking over* represents the physical symptoms that were becoming noticeable. Symptoms included everything from minor body and joints aches to Raynaud's phenomenon, gastrointestinal disorders, and respiratory complications, to integumentary changes on the face and body in the form of skin tightening. *Seeking answers* revolved around participants making appointments with their physician and included seeking

advice from friends and searching the internet based upon specific symptoms. *Being given the diagnosis* was both distressing and a sense of relief. Feelings of distress were felt knowing that there is no cure for scleroderma and that the trajectory of the disease was uncertain. Feelings of relief were felt by some knowing that at least they do not have to guess anymore about what was going on with their bodies. Participants could now move forward with treatment modalities in order to slow the progression of the disease. *Seeking support* describes how participants with scleroderma went about seeking support from friends and support groups in order to help deal with the changes taking place in their body and to help with their changing social environment. *Protecting self* was an internal process, where participants purposely made conscious decisions to protect their roles and to demonstrate to themselves that there was still some ability to maintain a sense of independence and control in their lives. Seeking support and protecting self was a reinforcing, circular process that contributed to both protecting self and maintaining a sense of self.

Ordinary Daily Living

In order to understand how systemic scleroderma had affected their lives, participants reflected back on who they were prior to systemic scleroderma. Ordinary daily living was the baseline from which everything else in their lives was compared to. Participants described themselves as being very active and fully involved in their daily lives. They were energetic, self-sufficient, independent, and feeling healthy. Janet noted, "I was very active and in good physical shape and did a lot of outdoor activities." Cynthia described her life, "Very active…worked. Very involved with my kids and grandchildren…a lot of friends…very active socially. Did a lot of volunteer work."

Disease Taking Over

All of the participants experienced sign and symptoms of systemic scleroderma taking over their body; however, none of them knew that what they were experiencing was related to systemic scleroderma. None of the women were officially diagnosed at this time. The most common symptom was the continuous body and joint aches. Raynaud's phenomenon was the second most common symptom, which prompted them to pay a visit to their primary physician. Brenda explained the progression, "I'd say around 2004. My fingers turned black, and then three fingers, and then jumped to the other hand." Several of the participants experienced gastrointestinal and respiratory complications, and the younger participants were confused as to why, at their age, they were having difficulty breathing after just walking. Ruth explained how the symptoms were aggressive and came on quickly, "It really progressed…the G.I. and lungs were affected right away. And the skin tightness and immobility. I couldn't do anything. I couldn't walk around my apartment without being unable to breath. Yeah … the symptoms came on really fast."

The biggest disappointment many of the participants expressed was the sense of frustration with their physicians. Many expressed how their physicians dismissed their symptoms as generalized pain and prescribed pain medication, or they were told to lose weight and exercise more or reduce stress. After taking the pain medication and following the advice from their physician, several continued to experience unrelieved pain. For some of the participants, the frustration was shared between them and their physician because their physician did everything and still could not figure out what was going on with their body. Many participants expressed that they sought out multiple providers because the healthcare providers themselves did not fully

understand what was going on and did not know which specialist to refer them to. They were beginning to feel defeated and hopeless, as described by Rebecca,

> She [physician] comes in. She was like I just don't know what to tell you. We've gone through every test I can think of and everything is coming back normal. I don't see anything that's wrong with you. I was so frustrated I started to cry.

Seeking Answers

Frustration led to seeking answers for themselves. All of the participants were trying to use all of the resources available to them. Seeking answers was a complex and laborious process. Seeking answers included getting a second medical opinion, talking with friends, and doing an internet search. Most of the participants were motivated to figure out, any way that they could, what was going on with their bodies. They were not satisfied with what they were being told by their physician and decided they needed to be their own advocate. For many, seeking advice from friends was a logical place to begin, as noted by Carolyn, "I've talked with a lot of my friends about it. I would call one of my friends and ask her advice, too." After several months had passed with no real answers and no definite diagnosis, most of the participants were referred by primary care to a rheumatologist who specializes in autoimmune diseases. Rachel described, "So I found another doctor and I went saw her. She referred me to a rheumatologist, and the rheumatologist diagnosed me with scleroderma and then got me in to see a scleroderma specialist." Once participants were under the care of a rheumatologist, they began to understand what was possibly going on with their bodies. Adding to this frustration was the fact that many of the signs and symptoms associated with scleroderma are also seen in individuals with lupus. Blood work and skin biopsies soon revealed they had systemic scleroderma.

Being Given the Diagnosis

Being given the diagnosis of systemic scleroderma was seen as both comforting and devastating at the same time. Having an official diagnosis allowed participants to move forward with a plan; however, having systemic scleroderma brought about feelings of deep uncertainty, catastrophic thinking, and feelings of doom. The biggest contributing factor leading to these deep feelings was the information they found on the internet. Many felt that having systemic scleroderma was a death sentence, as described by Janet,

> I mean, of course I'm scared that it's going to go into my face more and it makes the lips really thin and the teeth really big. I'm scared to death that it's going to happen and go into my lungs and my heart.

Carolyn also noted, "I didn't know…I kind of felt like it was a death sentence." Some participants were concerned about how systemic scleroderma was going to affect their face and skin. Nicole stated, "The thought of my, you know, essentially looking like a mummy was horrifying." Several participants also expressed how their quality of life was decreasing and that they were now beginning to struggle through their symptoms. This led to thoughts of "why me" and reflecting back to what they had done in their past life to deserve this terrible disease.

Seeking Support

Finding a support group was crucial to how participants dealt with living with systemic scleroderma. Being part of a support group not only helped participants emotionally work through the changes taking place with their bodies, support groups were also a great place for participants to become more educated about systemic scleroderma and to learn how to adapt. Sharing their experiences with others was important, as described by Carolyn,

> So, I think that's really been helpful…helping me manage it all…that I'm not isolating myself at all. I'm like that support group.…I try to go when I can and it does have really, really good friends and like a supportive family.
> .

Being around people who have scleroderma brought about a sense of comfort, belonging, and a kind of recognition that participants did not get outside of the support group. Angela noted, "I've noticed too, when I look at other people who have it [scleroderma], we all have the same look and lose face or something."

Protecting Self

Protecting self was an internal process that participants did in order to hold on to as much of their independence as possible. Protecting self was also a way that participants tried to convince themselves that they were still who they knew themselves to be, as described by Melissa, "You push through and carry on and pretend you don't have anything wrong with you…and I was good at that." Many of the participants were determined to not give up what they enjoyed. Being persistent and persevering through the physical consequences of systemic scleroderma was necessary in order to prevent themselves from succumbing to systemic scleroderma. Heather explained,

> I still think that I'm a strong enough person. If I find ways to do it myself…if I find ways to overcome something, I'll do it. So, I would say that's my personality. I'm not going to let things stop me.

Roles and family obligations were also important to protect. Debra noted,

> You know, my kids are still pretty young to where they have field trips, and it might not be in my best interest to go to the zoo or go to the museum because I'm not feeling well, but I'm not going to miss that, and I'm not gonna let this bring me down that far, so in that role [mother], I've tried to be strong.

Protecting self also meant not allowing scleroderma to define who you are and showing to the outside world that you still are independent and able to live your life, as described by Nicole, "For me, it was my way of showing people that, look, I'm a real person, you know. I didn't want or let it [scleroderma] define me because I still am a strong, independent woman."

The subcategories, *seeking support* and *protecting self*, were seen as being fundamental in helping participants adapt to the changes taking place—both in their bodies and in their lives. Participants in this study saw both as being integral to how they adapted to living with systemic scleroderma. Seeking support and protecting self were also seen as having a bidirectional relationship. Seeking support was another way at attempting to protect self, which in turn, drove them to seek support.

Summary

Chapter IV detailed the grounded theory about the process of identity management in individuals living with systemic scleroderma. The core categories that emerged from this study were adapting to changes, dismantling of self, reclaiming self, and embracing self. Six subcategories emerged under adapting to changes that helped to explain the process of adapting to the changes.

Chapter V: Discussion and Recommendations

Four major categories emerged from the grounded theory study of identity management in individuals living with systemic scleroderma: (a) adapting to changes, (b) dismantling of self, (c) reclaiming self, and (d) embracing self. The subcategories found under adapting to changes elucidate the steps participants move through in an effort to better understand what is happening to their bodies, while simultaneously trying to protect self and identity. Paradoxically, dismantling of self is also occurring simultaneously with protecting self. This chapter will discuss the findings in relation to the supporting literature, beginning with the most significant findings, and will follow with limitations and strengths of the study, implications for nursing theory and practice, and recommendations for future research.

Embracing Self

Embracing self was transformative. Individuals with systemic scleroderma moved through an internal process of letting go, reevaluating, and reclaiming. Embracing appeared to be synonymous with accepting. The chronic illness literature approaches accepting as a process that takes place, whereby an individual begins to live with their chronic illness, be it diabetes, COPD, or rheumatoid arthritis, and finds ways to self-manage their chronic illness. Individuals living with many debilitating chronic illnesses tend to view the term *accepting* as giving up or letting go (Telford, Kralik & Koch, 2006). This study suggests that embracing self is not synonymous with accepting. In the current study, embracing self was a way to reclaim a perceived lost identity by realizing that who one is, fundamentally, has not changed. This is different from a study by Robinson (2017), where the researcher found that for individuals living with a chronic illness, the turning point was beginning to look outside the self instead of inside the self. Looking outside the self was a way to restructure life and live beyond the illness. In this study, embracing

self begins by looking inside self and by doing so can allow one to live with intention. For many participants living with intention meant being grateful for where they were in their lives, enjoying the little things in life, and knowing that their life experience could benefit and support others living with systemic scleroderma.

Throughout this study, participants were able to identify positive and meaningful consequences of living with systemic scleroderma. These positive and meaningful consequences emerged from the process of reclaiming self, which led to embracing self. Embracing self allowed participants to rewrite and rebuild their biographies and to live with renewed intention and purpose (Kostova, Caiata-Zufferey, & Schulz, 2014). Embracing the self opened up space for participants to be grateful and for them to contribute to others living with systemic scleroderma.

Adapting to Changes

Adapting to changes was a major challenge for individuals living with systemic scleroderma. These changes included managing a limited activity level and growing insecurities related to maintaining independence, a declining physical body, and becoming dependent on someone else. This was comparable to the other studies focusing on chronic illness in general (Burles & Thomas, 2012; Burstrom et al., 2012), which found that participants struggled with losing their independence and fear of having to live with a frail and failing body. Losing independence was a major concern related to losing their sense of self or identity, and this was also reflected in this study (Joachim & Acorn, 2003; Oksel & Gunduzoglu, 2014).

All participants experienced various signs and symptoms as systemic scleroderma progressed. Many expressed how frustrated they were with trying to find an answer to what was going on within their bodies. This initial frustration was focused on the lack of information they

received from their physician. Most physicians dismissed their symptoms as being minor. What was even more confusing was the lack of information rheumatologists had about scleroderma. This is consistent with a study by Gumuchian et al. (2016), which revealed that participants experienced dissatisfaction navigating the healthcare system and the difficulty that participants had trying to communicate to their physicians about what they were experiencing. Burstrom et al. (2012) found similar results in their study, indicating that participants expressed a lack of faith in physicians, and this lack of faith came from feeling dismissed by physicians and not being taken seriously when presenting with the same symptoms over and over again. The daily struggle of living with systemic scleroderma was all part of understanding how the disease was taking over their lives. Not having a physician who understood what was going on made this experience even more frustrating.

Seeking support was a strong, positive intervention to coping with and living with systemic scleroderma. Support not only provided emotional strength, it also provided a way to normalize what was happening to their bodies and within their daily lives. Comparing themselves to others living with systemic scleroderma made participants feel like they were not alone, and in a way, they saw themselves as living similar lives. This provided a sense of belonging and comfort. This finding was consistent with a study by Heaton (2015), who found this same result looking at individuals living with various chronic illnesses.

Dismantling of Self

Another core category, dismantling of self, can be described as a sense of breaking down. Participants in this study described how systemic scleroderma had stolen their life and had taken their identity with it. Their bodies and lives changed right before their eyes. Many described feelings of uselessness, helplessness and betrayal. Biographical disruption, or the feeling that

there was a break in one's planned life continuity related to roles and identity (Hannum & Rubinstein, 2016), and feeling trapped by scleroderma were strong feelings conveyed by most of the participants. Loss quickly became a truth the moment participants realized their inability to manage their physical and personal lives. The chronic illness literature is abundant with studies revealing how one's life is disrupted by a chronic illness, especially if a chronic illness forces a person to drastically alter one's way of life. This study also revealed many of the changes seen in someone living with a chronic illness and is consistent with the study by Clarke and Bennett (2013), who revealed in their study of men and women and their experience of living with multiple chronic conditions later in life that individuals described their body changes and accompanying personal disruptions as undermining their sense of identity. Biographical disruption, fragmented time, and the sense that the imagined future and continuity of self was disconnected and destroyed all lead to the feeling of being dismantled, as similarly found in other studies (Hannum & Rubinstein, 2016; Lundman & Jansson, 2007).

Reclaiming Self

Reclaiming self was the basic social process for individuals living with systemic scleroderma. Reclaiming self was found to be a deeply reflective process that begins with allowing oneself to let go of what a person is still trying to hold on to, reevaluate what the person still can do, and reclaiming who they always knew they were inside. Reclaiming self is ultimately a journey about reclaiming identity. This is consistent with a study by Conti (2018), where identity and reclaiming were seen as being connected to defining a purpose and a sense of belonging.

Much of the current literature looking at identity and reclaiming of self appears to be related to gender, sexual identity, and marginalized individuals (Cerezo, Cummings, Holmes, &

Williams, 2020; Dziengel, 2014; van den Brink, Vollmann, & van Weelie, 2020; Winans-Solis, 2014). There also continues to be an abundant amount of current research looking at chronic illness (Meiers, Eggenberger, Krumwiede & Deppa, 2020; Kirkpatrick et al., 2018; Kristjansdottir et al., 2018; Robinson, Jones, & McPhee, 2020; Tecspn, Wilkinson, Smith, & Ko, 2019;); however, there appears to be a lack of current research specifically addressing the connection between identity and chronic illness. Most of the chronic illness literature concentrates on self-management and how self-management can lead to better outcomes for someone living with a chronic illness (Bauer & Schiffman, 2020; Pinchera, Delloiacono, & Lawless, 2018; Waverijn, Heijmans, & Groenewegen, 2017). It is clear from this study that identity is also an important component to self-manage systemic scleroderma.

Theoretical Integration

Self-concept is important to identity development and is instrumental in what someone believes about themselves, and it can include personal attributes (Baumeister, 1999; Forgas & Williams, 2002). According to social identity theory (Tajfel & Turner, 1986), self-concept is developed from two main elements: personal identity and social identity. Broadly speaking, personal identity is comprised of individual traits and characteristics said to create one's uniqueness. Social identity uniquely places one within social groups and allows one to participate within those groups. Findings from this study support the personal identity concept associated with self-concept. Although one's physical self may drastically change as a consequence of systemic scleroderma, the findings of this study reveal that one's inner core, which is comprised of individual traits and characteristics, does not change. The findings from this study suggest that the most important element of identity may be one's personal identity.

Personal identity allows one to embrace self in the challenge of a debilitating chronic disease, such as systemic scleroderma, and continue living with purpose and intention.

The CSM (Diefenbach and Leventhal, 1996) posits that making sense equates to common sense. For individuals living with systemic scleroderma, experiencing signs and symptoms helps make sense of systemic scleroderma, thereby contributing to their sense of loss and uncertainty. However, making sense of the experience of living with systemic scleroderma can also help achieve a good quality of life and to find positive changes to reclaim sense of self. The findings from this study support the CSM. Participants were able to reclaim their sense of self by reclaiming self and embracing self. For participants in this study, living with a renewed purpose and intention, being grateful, and appreciating their contributions to others all made sense of the scleroderma experience.

Scleroderma Studies

A brief literature search on scleroderma reveals that a tremendous amount of research continues to be conducted; however, research remains primarily focused on genetic and molecular studies in hopes of discovering how scleroderma is triggered and to hopefully discover a cure. There also is a large amount of research focusing on the interaction between systemic scleroderma and its effects on the cardiac, respiratory, and gastrointestinal systems. There was one article that focused on caring for patients with scleroderma (Lachner, 2016); however, that article was primarily informational in nature and not empirical. It is important that nurse scientists continue to research how scleroderma affects the individual and families. Understanding the disease trajectory of systemic scleroderma is important; however, nurses are experts in patient care and symptom management. Understanding the process of identity management can only enhance current findings and assist in bringing about a better

understanding of systemic scleroderma. A better understanding will also allow for better nursing interventions.

Limitations and Strengths

One limitation of this study was not collecting participant data on race or ethnicity, which limits understanding of any context race or ethnicity may have played in the process of identity management in individuals living with systemic scleroderma. A second limitation relates to how clinically heterogeneous participants were in relation to the progression of systemic scleroderma. Living with systemic scleroderma is a unique experience for each person, and the progression of systemic scleroderma does not follow a similar or predicted path for everyone. Several participants were living with systemic scleroderma for 10 years and had little internal involvement, while others have been living with systemic scleroderma for only four years and had significant internal involvement. The difference in the rates of disease progression may have had an impact on the process of identity management, and as a result, the findings may not be transferrable to everyone living with systemic scleroderma. A third limitation is that there likely was selection bias towards participants who had achieved a positive relationship with their condition. It is equally likely that people who had a negative experience did not offer to be interviewed for this study.

Despite these limitations, this study has several strengths. One strength was the range of the participant characteristics. The participants represented a wide range in age and number of years living with systemic scleroderma. Theoretical sampling was another strength of this study. Recruitment for this study resulted in 73 participants nationally interested in being interviewed. Through theoretical sampling, participants were able to be chosen based upon the purpose of the

study and what was emerging from the data; as a result, theoretical saturation was able to be achieved.

Implications for Nursing Practice

The findings of this study may help with creating future nursing interventions to assist with identity management of individuals living with systemic scleroderma or other chronic conditions. Nurses have an essential role in assisting patients to understand the whole process of living with and managing a chronic illness. This study's findings can also help nurses better understand that nursing care of patients with systemic scleroderma includes equal attention to both physical and psychological aspects of self-management. Within the individual and family self-management theory (Ryan & Sawin, 2009), the process of self-regulation includes emotional and cognitive responses, which may open up space to consider matters related to identity management. According to the IFSMT, there are three dimensions that are taken into consideration related to self-management of chronic conditions. These three dimensions are context, process, and outcomes. Findings from this study speak to the contextual dimension, which include the physiological, physical, and social environments and the process dimension, which include health behavior change. The IFSMT suggests that self-management of chronic conditions can lead to improved health outcomes. Audulv, Nornbergh, Asplund, and Hörnsten (2009) suggest that self-management of a chronic illness is an ongoing process of inner negotiation. The findings of the current study suggest that "Embracing self" may be a component of self-management for nurses to take into consideration, not only for individuals living with systemic scleroderma, but perhaps for a multitude of various other chronic illnesses where one's sense of self is being diminished as part of the disease process.

Findings suggest that identity is a significant component of the self, and how someone views the self may have an effect on how one copes with such a destructive autoimmune disease like scleroderma. For some, systemic scleroderma can rapidly change their life. Nurses can begin to help with the process of reclaiming self by helping individuals living with systemic scleroderma begin to explore their inner self before the disease begins to dismantle the physical self. This intervention can also lead to a better way of self-managing systemic scleroderma, which in turn can lead to a better sense of self. Nurses can also be instrumental in recognizing when an individual may benefit from psychotherapy to assist in coping with the challenges of living with systemic scleroderma. Referrals to psychotherapy, combined with other nursing interventions, may assist patients to better move through the negative outcomes related to the dismantling of self towards the more positive outcomes related to reclaiming self. Overall, psychotherapy may be instrumental in promoting self-management of systemic scleroderma.

Implications for Health Policy

Healthcare costs are a major concern for anyone living with a chronic condition. Adding to the complexity of living with a chronic illness are the comorbidities that accompany them, and systemic scleroderma is not without its own comorbidities. Unfortunately, the cost of treating and managing a chronic illness has become an economic burden for many who are living with a chronic illness. Patients with systemic scleroderma in the United States are seeing a higher direct and indirect economic burden and healthcare resource utilization postdiagnosis. Annual healthcare costs, which include inpatient and outpatient visits, as well as emergency room and pharmacy costs, can easily add up to $22,016 out-of-pocket expenses annually and has continued to rise over the past decade (Zhou et al., 2019). The largest indirect cost is related to work productivity. Many newly diagnosed scleroderma patients miss a significant amount of work due

to the onset and progression of the disease. Every participant in this study expressed how much scleroderma had affected their daily lives, especially in the beginning, due to painful onset of symptoms, the endless physician visits, and absenteeism from work.

The Scleroderma Foundation (www.scleroderma.org) provides several resources for individuals diagnosed with scleroderma. These resources include everything from a discussion board to a weekly electronic newsletter to information about how to find financial relief for medications and other medical services. It is imperative that funding continue from both public and private organizations to ensure that the financial burden may be lessened for individuals living with systemic scleroderma. In addition, both private and public health insurance plans must reconsider the initial costs associated with the onset and management of systemic scleroderma and realign reimbursement to reflect the direct costs associated with treating and managing systemic scleroderma.

Recommendations for Future Research

This grounded theory study focused on interviewing women who were living with systemic scleroderma. Future studies could include interviewing men who are living with systemic scleroderma. Men living with systemic scleroderma may have different experiences related to gender and the roles that come with gender. Findings from this grounded theory study may also serve as the groundwork for quantitative studies addressing particular concepts revealed in this study. Finally, this grounded theory study may also be used by other healthcare disciplines, such as psychology and sociology, to test with other individuals living with various other chronic illnesses.

Summary

This chapter discussed the study's findings and conceptual definitions related to the process of identity management in individuals living with systemic scleroderma. Strengths and limitations of the study were discussed, as well as recommendations for future research and health policy.

References

Aksan, N., Kisac, B., Aydin, M., & Demirbuken, S. (2009). Symbolic interaction theory. *Procedia-Social and Behavioral Sciences*, *1*(1), 902-904. doi:10.1016/j.sbspro.2009.01.160

Ambrosio, L., Garcia, J. M., Fernandez, M. R., Bravo, S. A., Ayesa, S., Sesma, M. E., … Portillo, M. C. (2015). Living with chronic illness in adults: A concept analysis. *Journal of Clinical Nursing, 24*(17-18)*,* 2357-2367. doi:10.1111/jocn.12827

Audulv, Å., Norbergh, K., Asplund, K., & Hörnsten, Å. (2009). An ongoing process of inner negotiation – A grounded theory study of self-management among people living with chronic illness. *Journal of Nursing & Healthcare of Chronic Illnesses*, *1*(4), 283-293. doi:10.1111/j.1752-9824.2009.01039.x

Azmitia, M. (2015). Reflections on the cultural lenses of identity development. In K. C. McLean, & M. Syed (Eds.), *The Oxford handbook of identity development* (pp. 286-298). New York, NY: Oxford University Press.

Barnes, J. K., & Mayes, M. D. (2013). Epidemiology and environmental risk factors. In J. Varga, C. P. Denton, & F. M. Wigley (Eds.), *Scleroderma: From pathogenesis to comprehensive management* (pp. 17-28). New York, NY: Springer.

Bauer, W. S., & Schiffman, R. F. (2020). Factors influencing self-management of chronic obstructive pulmonary disease by community-dwelling adults. *Western Journal of Nursing Research, 42*(6), 423-430. doi:10.1177/0193945919865532

Baumeister, R. F. (1999). The nature and structure of the self: An overview. In R. Baumeister (Ed.), *The self in social psychology* (pp. 1-20). Philadelphia, PA: Taylor & Francis Group.

Bem, S. L. (1981). Gender schema theory: A cognitive account of sex typing. *Psychological Review, 88*(4), 354. doi:10.1037//0033-295x.88.4.354

Benrud-Larson, L. M., Heinberg, L. J., Boling C., Reed, J., White, B., Wigley, F. M., & Haythornthwaite, J. A. (2003). Body image dissatisfaction among women with scleroderma: Extent and relationship to psychosocial function. *Health Psychology, 22*(2), 130-139. doi:10.1037/0278-6133.22.2.130

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western Journal of Nursing Research, 33*(7), 916-932. doi:10.1177/0193945910384602

Bergsten, U., Bergman, S., Fridlund, B., & Arvidsson, B. (2011). "Striving for a good life": The management of rheumatoid arthritis as experienced by patients. *Open Nursing Journal, 5,* 95-101. doi:10.2174/1874434601105010095

Blumer, H. (1969). *Symbolic interactionism.* Englewood Cliffs, NJ: Prentice Hall.

Bolster, M. B., & Silver, R. S. (2011). Clinical features of systemic scleroderma. In M. C. Hochberg, A. J. Silman, J. S. Smolen, M. E. Weinblatt, & M. H. Weisman (Eds.), *Rheumatology* (5th ed., pp. 1165-1176). Philadelphia, PA: Mosby.

Brown, R. L. (2015). Perceived stigma among people with chronic health conditions: The influence of age, stressor exposure, and psychosocial resources. *Research on Aging, 37*(4), 335-360. doi:10.1177/0164027514533133

Buck, U., Poole, J., & Mendelson, C. (2010). Factors related to self-efficacy in persons with scleroderma. *Musculoskeletal Care, 8*(4), 197-203. doi:10.1002/msc.181

Burke, P. J., & Stets, J. E. (2009). *Identity theory.* New York, NY: Oxford University Press.

Burles, M., & Thomas, R. (2012). "But they're happening to you at the wrong time": Exploring young adult women's reflections on serious illness through photovoice. *Qualitative Social Work, 12*(5), 671-688. doi:10.1177/1473325012450484

Burstrom, M., Brannatrom, M., Boman, K., & Strandberg, G. (2012). Life experiences of security and insecurity among women with chronic heart failure. *Journal of Advanced Nursing, 68*(4), 816-825. doi:10.1111/j.1365-2648.2011.05782.x

Caiola, C., Docherty, S. L., Relf, M., & Barroso, J. (2014). Using an intersectional approach to study the impact of social determinants of health for African American mothers living with HIV. *Advances in Nursing Science., 37*(4), 287. doi:10.1097/ANS.0000000000000046

Centers for Disease Control and Prevention (2016a). *Chronic disease prevention and health promotion*. Retrieved from https://www.cdc.gov/chronicdisease/overview/

Centers for Disease Control and Prevention (2016b). *Chronic obstructive pulmonary disease.* Retrieved from https://www.cdc.gov/copd/index.html

Cerezo, A., Cummings, M., Holmes, M., & Williams, C. (2020). Identity as resistance: Identity formation at the intersection of race, gender identity, and sexual orientation. *Psychology of Women Quarterly*, *44*(1), 67-83. doi:10.1177/0361684319875977

Chaboyer, W., Lee, B. O., Wallis, M., Gillespie, B., & Jones, C. (2010). Illness representations predict health-related quality of life 6 months after hospital discharge in individuals with injury: A predictive survey. *Journal of Advanced Nursing 66*(12), 2743-2750. doi:10.1111/j.1365-2648.2010.05431.x

Chang, Y. M., Tsao, L. I., & Huang, M. H. (2014). Experiences of coexisting with chronic illnesses among elderly women in communities. *Health Care for Women International, 35*(11-12), 1339-1353. doi:10.1080/07399332.2014.942905

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195. doi:10.1111/1467-9566.ep10491512

Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Sociology of Science and Medicine, 30*(11), 1161-1172. doi:10.1016/0277-9536(90)90256-r

Charmaz, K. (1995). The body, identity, and self. *Sociological Quarterly, 36*(4), 657-680. doi:10.1111/j.1533-8525.1995.tb00459.x

Charmaz, K. (2008). Grounded theory as an emergent method. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 155-172). New York, NY: Guilford Press.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.

Cinar, F. I., Unver, V., Cintar, M., Yilmaz, S., Simsek, I., Tosun, N., … Dinc, A. (2013). Coping strategies for activities of daily living in women whose hands are affected by systemic scleroderma. *Journal of Clinical Nursing, 23*(11-12), 1630-1638. doi:10.1111/jocn.12283

Clarke, L. H., & Bennett, E. (2013). "You learn to live with all the things that are wrong with you": Gender and the experience of multiple chronic conditions in later life. *Aging and Society, 33*(2), 342-360. doi:10.1017/s0144686x11001243

Cleveland Clinic Center for Continuing Education. (2017). *Systemic scleroderma.* Retrieved from http://www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/rheumatology/systemic-sclerosis/

Collier, M. J., & Thomas, M. (1988). Identity in intercultural communication: An interpretive perspective. In Y. Y. Kim, & W. B. Gudykunst (Eds.), *Theories of intercultural communication, International and Intercultural Communication Annual* (Vol. 12, pp. 99-120). Newbury Park, CA: SAGE.

Conti, J. E. (2018). Recovering identity from anorexia nervosa: Women's constructions of their experiences of recovery from anorexia nervosa over 10 years. *Journal of Constructivist Psychology*, *31*(1), 72–94. doi:10.1080/10720537.2016.1251366

Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher, 18*(4), 17-22. doi:10.7748/nr2011.07.18.4.17.c8631

Corbin, J., & Strauss, A. L. (1988). *Unending work and care: Managing chronic illness at home.* San Francisco, CA: Jossey-Bass.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*(1), 3-21. doi:10.1007/bf00988593

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research* (3rd ed.). Los Angeles, CA: Sage.

Cowan, G., Bommersbach, M., & Curtis, S. R. (1995). Codependency, loss of self, and power. *Psychology of Women Quarterly, 19*(2), 221-236. doi:10.1111/j.1471-6402.1995.tb00289.x

Descartes, R. (2000). *Discourse on method and related writings* (D. M. Clarke, Trans.). New York, NY: Penguin. (Original work published in 1637).

Devins, G. M., Bezjak, A., Mah, K., Loblaw, D. A., & Gotowiec, A. P. (2006). Context moderates illness-induced lifestyle disruptions across life domains: A test of the illness intrusiveness theoretical framework in six common cancers. *Psycho-Oncology, 15*(3), 221-233. doi:10.1002/pon.940

Dickson, A., Knussen, C., & Flowers, P. (2008). That was my old life; it's almost like a past-life now: Identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome. *Psychology and Health 23*(4), 459-476. doi:10.1080/08870440701757393

Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless, 5*(1)*,* 11-38. doi:10.1007/bf02090456

Dziengel, L. (2014). Renaming, reclaiming, renewing the self: Intersections of gender, identity, and health care. *Affilia: Journal of Women & Social Work*, *29*(1), 105-110. doi:10.1177/0886109913510660

Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2015). Stigma and racial/ethnic HIV disparities: Moving toward resilience. *Stigma and Health, 1*, 60-74. doi:10.1037/2376-6972.1.S.60

Earnshaw, V. A., Quinn, D. M., & Park, C. L. (2011). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness, 8*(2), 79-88. doi:10.1177/1742395311429393

Erikson, E. H. (1950). *Childhood and society.* New York, NY: Norton.

Erikson, E. H. (1968). *Identity: Youth and crisis.* New York, NY: Norton.

Fawcett, J., & Garity, J. (2009). *Evaluating research for evidence-based nursing practice*. Philadelphia, PA: F. A. Davis.

Flensner, G., & Rudolfsson, G. (2016). Learning to fly with broken wings: Forcing a reappraisal of time and space. *Scandinavian Journal of Caring Sciences, 30*(2), 403-410. doi:10.1111/scs.12262

Forgas, J. P., & Williams, K. D. (2002). *The social self: Cognitive, interpersonal and intergroup perspectives.* New York, NY: Psychology Press.

Ghabrial, M. A. (2017). "Trying to figure out where we belong": Narratives of racialized sexual minorities on community, identity, discrimination, and health. *Sexuality Research & Social Policy, 14*(1), 42-55. doi:10.1007/s13178-016-0229-x

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social Problems, 12*(4), 436-445. doi:10.1525/sp.1965.12.4.03a00070

Glaser, B. G. (1992). *Emerging vs. forcing: Basics of grounded theory analysis.* Mill Valley, CA: Sociology Press.

Glaser, B. G., & Holton, J. (2004). Remodeling grounded theory. *Forum: Qualitative Social Research, 5*(2). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/607/1315

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago, IL: Aldine Publishing Company.

Glaser, B. G., & Strauss, A. L. (1975). *Chronic illness and the quality of life.* Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (2008). *The discovery of grounded theory: Strategies for qualitative research.* Piscataway, NJ: Aldine Transaction.

Goffman, E. (1963). *Stigma: Notes on management of spoiled identity.* Englewood Cliffs, NJ: Prentice Hall.

Grove, S. K., Burns, N., & Gray, J. R. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (7th ed.). Philadelphia, PA: Elsevier Saunders.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation.* Newbury Park, CA: Sage.

Gumuchian, S. T., Pelaez, S., Delisle, V. C., Carrier, M-E., Jewlett, L. R., El-Baalbaki, G., … Thomas, B. D. (2016). Exploring sources of emotional distress among people living with scleroderma: A focus group study. *PloS ONE, 11*(3), 1-15. doi:10.1371/journal.pone.0152419

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184. doi:10.1080/088704403100081321

Hammack, P. L. (2015). *Theoretical foundations of identity*. In K. C. McLean & M. Syed, *The Oxford handbook of identity development* (pp. 11-32). New York, NY: Oxford University Press.

Hannum, S. M., & Rubinstein, R. L. (2016). The meaningfulness of time: Narratives of cancer among chronically ill older adults. *Journal of Aging Studies, 36*, 17-25. doi:10.1016/j.jaging.2015.12.006

Harman, G., & Clare, L. (2006). Illness representations and lived experience in early stage dementia. *Quality Health Research 16*(4), 484-502. doi:10.1177/10497323306286851

Heaton, J. (2015). Use of social comparisons in interviews about young adults' experiences of chronic illness. *Qualitative Health Research,25*(3), 336-347. doi:10.1177/1049732314553122

Heinberg, L. J., Kudel, I., White, B., Kwan, A., Medley, K., Wigley, F., & Haythornthwaite, J. (2007). Assessing body image in patients with systemic sclerosis (scleroderma): Validation of the adapted satisfaction and appearance scale. *Body Image, 4*(1)*,* 79-86. doi:10.1016/j.bodyim.2006.11.002

Hernandez, C.A. (2010). Getting grounded: Using Glaserian grounded theory to conduct nursing research. *Clinical Journal of Nursing Research, 42*(1), 150-163. Retrieved from http://cjnr.archive.mcgill.ca/article/view/2241

Hornboonherm, P., Nanagara, R., Kochamat, A., & Wantha, O. (2016). Self-care behaviours and trajectory management by people with scleroderma in northeastern Thailand. *International Journal of Nursing Practice, 23*(3), e12523. doi:10.1111/ijn.12523

Hoth, K. F., Wambolt, F. S., Strand, M., Ford, D. W., Sandhaus, R. A., Strange, C., … Holm, K. E. (2013). Prospective impact of illness uncertainty on outcomes in chronic lung disease. *Health Psychology, 32*(11), 1170-1174. doi:10.1037/a0032721

Hume, D. (1986). *A treatise of human nature.* New York, NY: Penguin. (Original work published 1739).

James, W. (1890). *The principles of psychology.* New York, NY: Henry Holt.

Jewett, L. R., Hudson, M., Malcarne, V. L., Baron, M., & Thombs, B. D. (2012). Sociodemographic and disease correlates of body image distress among patients with systemic sclerosis. *PloS ONE, 7*(3), e33281. doi:10.1371/journal.pone.0033281

Joachim, G., & Acorn, S. (2003). Life with a rare chronic disease: The scleroderma experience. *Journal of Advanced Nursing, 42*(6), 598-606. doi:10.1046/j.1365-2648.2003.02663.x

Joesey, T. (2016). Time and chronic illness: A narrative review. *Quality of Life Research, 25*(5), 1093-1102. doi:10.1007/s11136-015-1169-2

Johns Hopkins Medicine. (2017). *Johns Hopkins scleroderma center.* Retrieved from https://www.hopkinsscleroderma.org/

Kant, I. (2007). *Critique of pure reason* (M. Weight, Trans.). New York, NY: Penguin. (Original work published 1781).

Karnilowicz, W. (2001). Identity and psychological ownership in chronic illness and disease state. *European Journal of Cancer Care, 20*(2)*,* 276-282. doi:10.1111/j.1365-2354.2010.01220.x

Kirkpatrick, S., Locock, L., Farre, A., Ryan, S., Salisbury, H., & McDonagh, J. E. (2018). Untimely illness: When diagnosis does not match age□related expectations. *Health Expectations*, *21*(4), 730-740. doi:10.1111/hex.12669

Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: The case for reflexivity. *Journal of Advanced Nursing, 28*(4), 882-890. doi:10.1046/j.1365-2648.1998.00725.x

Kostova, Z., Caiata-Zufferey, M., & Schulz, P. J. (2014). The process of acceptance among rheumatoid arthritis patients in Switzerland: A qualitative study. *Pain Research & Management*, *19*(2), 61-68. doi:10.1155/2014/168472

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. doi:10.1046/j.1365-2648.2001.01704.x

Kristjansdottir, O. B., Stenberg, U., Mirkovic, J., Krogseth, T., Ljoså, T. M., Stange, K. C., & Ruland, C. M. (2018). Personal strengths reported by people with chronic illness: A qualitative study. *Health Expectations*, *21*(4), 787-795. doi:10.1111/hex.12674

Lachner, K. (2016). Caring for the patient with limited systemic scleroderma. *Orthopaedic Nursing*, *35*, 5-10. doi:10.1097/NOR.0000000000000212

Larsen, P. D. (2013). The illness experience. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and intervention* (8th ed., pp. 23-45). Burlington, MA: Jones and Bartlett.

Lebel, S., Castonguay, M., Mackness, G., Irish, J., Bezjak, A., & Devins, G. M. (2013). The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-Oncology, 22*(1), 140-152. doi:10.102/pon.2063

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense model of illness danger. In S. Rachman (Ed.), *Medical psychology* (Vol. 2, pp. 7-30). New York, NY: Pergamon.

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of psychology and health: Social psychological aspects of health* (Vol. 4, pp. 219-252). Hillsdale, NJ: Earlbaum.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lindsay, H., MacGregor, C., & Fry, M. (2014). The experience of living with chronic illness for the haemodialysis patient: An interpretive phenomenological analysis. *Health Sociology Review, 23*(3), 232-241. doi:10.1080/14461242.2014.11081976

Livingstone, W., Van De Mortel, T., & Taylor, B. (2011). A path of perpetual resilience: Exploring the experience of a diabetes-related amputation through grounded theory. *Contemporary Nurse, 39*(1), 20-30. doi:10.5172/conu.2011.39.1.20

Locke, J. (1998). *An essay concerning human understanding* (2nd ed.). New York, NY: Penguin. (Original work published 1694).

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

Martin, C. M. (2007). Chronic disease and illness care: Adding principles of family medicine to address ongoing health system redesign. *Canadian Family Physician, 53*(12), 2086-2091. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2231531/

Matthie, N., Hamilton, J., Wells, D., & Jeneretta, C. (2016). Perceptions of young adults with sickle cell disease concerning their disease experience. *Journal of Advanced Nursing, 72*(6), 1441-1451. doi:10.1111/jan.12760

Maz, J. (2013). Employing a grounded theory approach: Core characteristics. *British Journal of Cardiac Nursing 8*(9), 453-458. doi:10.12968/bjca.2013.8.9.453

McCall, G. J., & Simmons, J. L. (1966). *Identities and interactions: An examination of human associations in everyday life.* New York, NY: Free Press.

Mead, G. H. (1934). *Mind, self and society.* Chicago, IL: University of Chicago Press.

Meiers, S. J., Eggenberger, S. K., Krumwiede, N. K., & Deppa, B. (2020). Measuring family members' experiences of integrating chronic illness into family life: Preliminary validity and reliability of the family integration experience scale: chronic illness (FIES:CI). *Journal of Family Nursing*, *26*(2), 111-125. doi:10.1177/1074840720902129

Mendelson, C. (2006). Managing a medically and socially complex life: Women living with lupus. *Qualitative Health Research 16*(7), 982-997. doi:10.1177/1049732306290132

Mora-Rios, J. (2016). Subjective experience and resources for coping with stigma in people with a diagnosis of schizophrenia: An intersectional approach. *Qualitative Health Research., 26*(5), 697-711. doi:10.1177/1049732315570118

Nakayama, A., Tunnicliffe, D. J., Thakkar, V., Singh-Grewal, D., O'Neill, S., Craig, J. C., & Tong, A. (2016). Patients' perspectives and experiences living with systemic scleroderma: A systematic review and thematic synthesis of qualitative studies. *Journal of Rheumatology, 43*(7), 1363-1375. doi:10.3899/jrheum.151309

Neville, C., Costa, D. D., Mill, C., Rochon, M., Avina-Zubieta, J. A., Pineau, C. A., … Fortin, P. R. (2013). The needs of persons with lupus and health care providers: A qualitative study aimed toward the development of the lupus interactive navigator. *Lupus, 23*(2), 176-182. doi:10.1177/0961203313517154

Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine, 46*(7), 869-878. doi:10.1016/s0277-9536(97)00211-6

Oksel, E., & Gunduzoglu, N. C. (2014). Investigation of life experiences of women with scleroderma. *Sexuality & Disability, 32*(1)*,* 15-21. doi:10.1007/s11195-013-9334-4

Pastorino, E. E., & Doyle-Portillo, S. M. (2016). *What Is psychology? Foundations, applications, and integration*. Boston, MA: Cengage Learning.

Petty, N. J., Thomson, O. P., & Stew, G. (2012). Ready for a paradigm shift? Part 2: Introducing qualitative research methodologies and methods. *Manual Therapy, 17*(5), 378-384. doi:10.1016/j.math.2012.03.004

Pinchera, B., Delloiacono, D., & Lawless, C. A. (2018). Best practices for patient self-management: Implications for nurse educators, patient educators, and program developers. *Journal of Continuing Education in Nursing*, *49*(9), 432-440. doi:10.3928/00220124-20180813-09

Poteat, T., German, D., & Kerrigan, D. (2013). Managing uncertainty: A grounded theory of stigma in transgender health care encounters. *Social Science and Medicine, 84,* 22-29. doi:10.1016/j.socscimed.2013.02.019

Purc-Stephenson, R., Bowlby, D., & Qaqish, S. T. (2015). "A gift wrapped in barbed wire": Positive and negative life changes after being diagnosed with irritable bowel disease. *Quality Life Research, 24*(5)*,* 1197-1205. doi:10.1007/s11136-014-0843-0

Robinson, C. A. (2017). Families living well with chronic illness: The healing process of moving on. *Qualitative Health Research*, *27*(4), 447-461. doi:10.1177/1049732316675590

Robinson, W. D., Jones, A. C., & McPhee, D. P. (2020). Living with a rare chronic illness: A phenomenological, systemic examination of hemophilia complicated by an inhibitor. *American Journal of Family Therapy*, *48*(3), 250-270. doi:10.1080/01926187.2019.1708831

Rodnan, G. P., Lipinski, E., & Luksick, J. (1979). Skin thickness and collagen content in progressive systemic scleroderma and localized scleroderma. *Arthritis and Rheumatism, 22*(2), 130-140. doi:10.1002/art.1780220205

Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, *57*(4), 217-225.e6. doi:10.1016/j.outlook.2008.10.004

Scleroderma Foundation (2020). Retrieved from https://www.scleroderma.org

Singh, M. K., Clements, P. J., Furst, D. E., Maranian, P., & Khanna, D. (2012). Work productivity in scleroderma: Analysis from the University of California, Los Angeles scleroderma quality of life study. *Arthritis Care & Research*, *64*(2), 176-183. doi:10.1002/acr.20676

Skaff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *Gerontologist, 32*(5), 656-664. doi:10.1093/geront/32.5.656

Stets, E. J., & Burke, P. J. (2000). Identity theory and social identity theory. *Social Psychology Quarterly, 63*(3), 224-237. doi:10.2307/2695870

Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly, 63*(4), 284-297. doi:10.2307/2695840

Stuenkel, D. L., & Wong, V. K. (2013). Stigma. In I. M Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and intervention* (8th ed., pp. 47-74). Burlington, MA: Jones and Bartlett.

Tajfel, H., & Turner, J. (1986). The social identity theory of inter-group behavior. In S. Worchel & W. Austin (Eds.), *Psychology of intergroup relations* (pp. 7-24). Chicago, IL: Nelson-Hall.

Tecson, K. M., Wilkinson, L. R., Smith, B., & Ko, J. M. (2019). Association between psychological resilience and subjective well-being in older adults living with chronic illness. *Baylor University Medical Center Proceedings*, *32*(4), 520-524. doi:10.1080/08998280.2019.1625660

Telford, K., Kralik, D., & Koch, T. (2006). Acceptance and denial: Implications for people adapting to chronic illness: Literature review. *Journal of Advanced Nursing, 55*(4)*,* 457-464. doi: 10.1111/j.1365-2648.2006.03942.x

Tennen, H., & Affleck, G. (2002). Benefit-finding and benefit-reminding. In C. R. Snyder & S. J. Lopez (Eds.), *The handbook of positive psychology* (pp. 584-597). New York, NY: Oxford University Press.

Thornhill, K., Lyons, A. C., Nouwen, A., & Lip, G. W. H. (2008). Experiences of living with congested heart failure: A qualitative study. *British Journal of Health Psychology, 13*(1), 155-175. doi:10.1348/135910706X170983

Vallido, T., Wilkes, L., Carter, B., & Jackson, D. (2010). Mothering disrupted by illness: A narrative synthesis of qualitative research. *Journal of Advanced Nursing, 66*(7), 1435-1445. doi:10.1111/j.13652648.2010.05350.x

van Den Brink, F., Vollman, M., & van Weelie, S. (2019). Relationships between transgender congruence, gender identity rumination, and self-esteem in transgender and gender-nonconforming individuals. *Psychology of Sexual Orientation and Gender Identity, 7*(2), 230-235. doi:10.1037/sgd0000357

Van Gennip, I. E., Pasman, H. R. W., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen B. D. (2015). Dynamics in the sense of dignity over the course of illness: A longitudinal study into the perspectives of seriously ill patients. *International Journal of Nursing Studies, 52*(11), 1694-1704. doi:10.1016/j.ijnurstu.2015.06.010

Waterman, A. S. (2015). Identity as internal processes: How the "I" comes to define the "me". In K. C. McLean & M. Syed (Eds.), *The Oxford handbook of identity development* (pp. 195-209). New York, NY: Oxford University Press.

Winans-Solis, J. (2014). Reclaiming power and identity: Marginalized students' experiences of service-learning. *Equity & Excellence in Education*, *47*(4), 604-621. doi:10.1080/10665684.2014.959267

Waverijn, G., Heijmans, M., & Groenewegen, P. P. (2017). Chronic illness self-management: A mechanism behind the relationship between neighbourhood social capital and health? *European Journal of Public Health, 27*(4), 594-599. doi:10.1093/eurpub/ckw185

World Health Organization (2005). *Noncommunicable diseases.* Retrieved from http://www.who.int/topics/noncommunicable_diseases/en/

Zhou, Z., Fan, Y., Thomason, D., Tang, W., Liu, X., Zhou, Z-Y., Macaulay, D., & Fischer, A. (2019). Economic burden of illness among commercially insured patients with system schlerosis with interstitial lung disease in the USA: A claims data analysis. *Advances in Therapy, 36*(5), 1100-1113. doi:10.1007/s12325-019-00929-2

Appendix A

Demographics

Participant:_____ Date:_____
(Pseudonym/ID #)

Age: _____

Gender: _____

Employment: Working _____ Not Working _____

P/T _____ F/T _____

Title/type of work _____

_____

Relationship status:

Married _____ Divorced _____ Partnered _____ Single _____

Years married _____

Children:

Y _____ How many _____ age(s) _____

N _____

Number of years living with systemic scleroderma _____

Do you have any other medical conditions that you are living with besides scleroderma?

Yes: _____ No: _____

If yes, what are these other medical conditions:

Appendix B

Semi-Structured Interview Questionnaire

1) Tell me who you were before scleroderma?

2) How long has it been since you were diagnosed with systemic scleroderma?

3) Tell me what it was like to hear that you have systemic scleroderma?

4) Tell me what lead up to you being diagnosed with systemic scleroderma. How long did it take to be diagnosed? When did you know something wasn't right? How long passed from when you had symptoms and when you were diagnosed?

5) What were you thinking and how did this make you feel?

6) How did you handle (manage) that change?

7) When did you notice your life changing more rapidly due to your illness progression?

8) How have you handled (managed) these other changes?

9) How do you think about yourself when you look at yourself/body? What do you think is (are) the reason(s) why you think this way about yourself?

10) Tell me about a time when you noticed other people looking or reacting to you having scleroderma? How did this make you feel?

11) How did (do) you handle (manage) these feelings?

12) Thinking about the roles that you represent or play in your life, how have these roles changed?

13) Tell me about a time when you felt that scleroderma had threatened or disrupted who you saw yourself as being (identity)? How did that make you feel?

14) What have you done to manage/protect your sense of who you are (identity) and how have you done this?

15) Tell me about a time when it was hard to cope. When it was hard to think about the future?

16) Have you found or discovered anything positive about having systemic scleroderma?

17) Tell me about a time how this positive discovery changed you?

Appendix C

Semi-Structured Interview Questionnaire (Amended)

1) Tell me who you were before scleroderma?

2) How long has it been since you were diagnosed with systemic scleroderma?

3) Tell me what it was like to hear that you have systemic scleroderma?

4) Tell me what lead up to you being diagnosed with systemic scleroderma. How long did it take to be diagnosed? When did you know something wasn't right? How long passed from when you had symptoms and when you were diagnosed?

5) What were you thinking and how did this make you feel?

6) How did you handle (manage) that change?

7) When did you notice your life changing more rapidly due to your illness progression?

8) How have you handled (managed) these other changes?

9) How do you think about yourself when you look at yourself/body? What do you think is (are) the reason(s) why you think this way about yourself?

10) Tell me about a time when you noticed other people looking or reacting to you having scleroderma? How did this make you feel?

11) How did (do) you handle (manage) these feelings?

12) Thinking about the roles that you represent or play in your life, how have these roles changed?

13) What does identity mean to you? What is your understanding of identity?

14) Tell me about a time when you felt that scleroderma had threatened or disrupted who you saw yourself as being (identity)? How did that make you feel?

15) What have you done to manage/protect your sense of who you are (identity) and how have you done this?

16) Tell me about a time when it was hard to cope. When it was hard to think about the future?

17) Have you found or discovered anything positive about having systemic scleroderma?

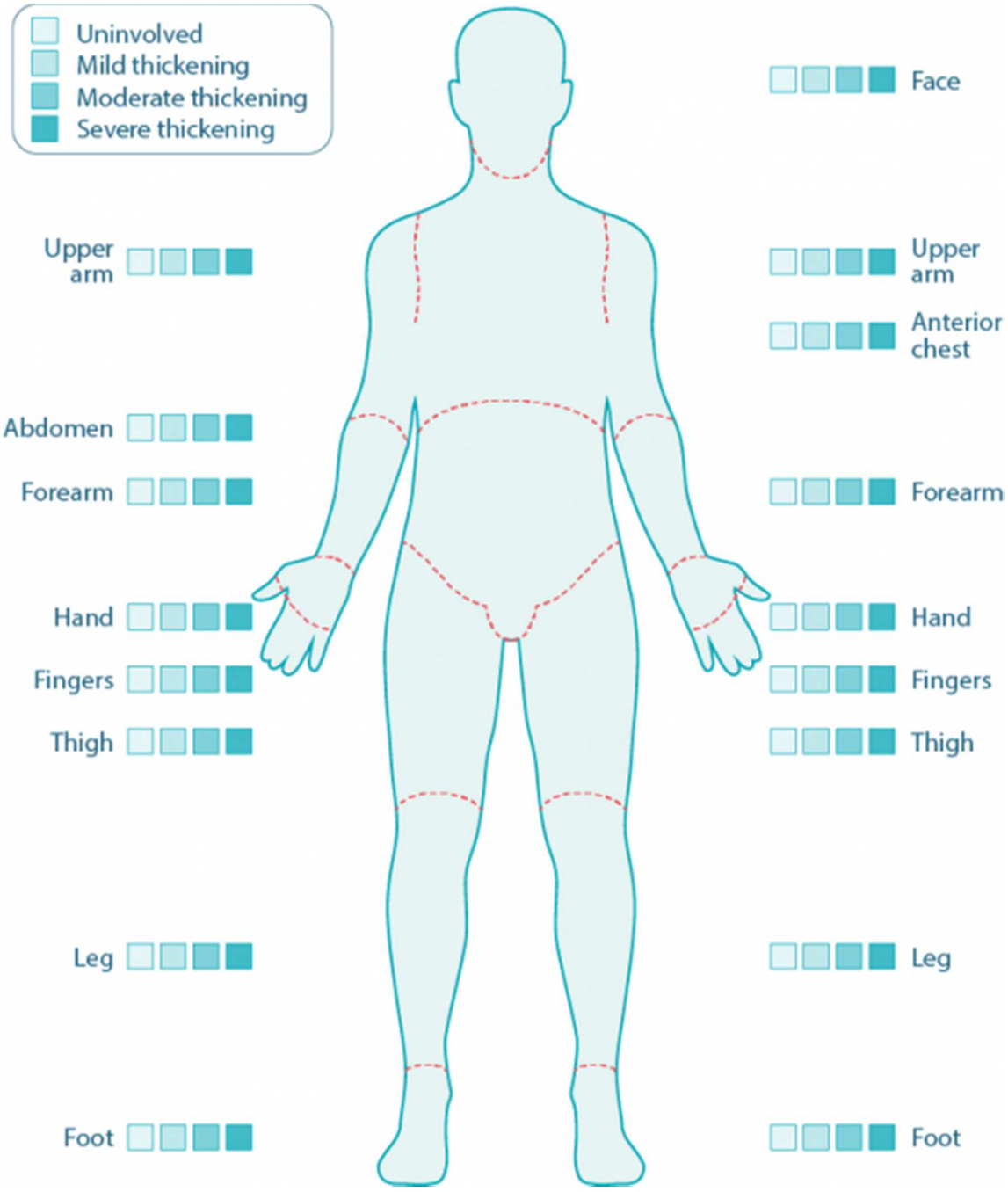
18) Tell me about a time how this positive discovery changed you?

19) Is there anything else you would like to add to this interview about your experience of living with systemic scleroderma?

Appendix D

Modified Rodnan Skin Score

Score: Uninvolved = 0 Mild Thickness = 1 Moderate Thickness = 2 Severe Thickness = 3



Appendix E

Institutional Review Board Approval

UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Leah Stoiber
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-7455 *phone*
(414) 229-6729 *fax*

http://www.irb.uwm.edu
lstoiber@uwm.edu

New Study - Notice of IRB Expedited Approval

Date: June 29, 2018

To: Jennifer Doering, PhD
Dept: College of Nursing

CC: Donald Miller

IRB#: 18.285
Title: The Experience of Living with Systemic Scleroderma

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 6 and 7 as governed by 45 CFR 46.110.

This protocol has been approved on **June 29, 2018** for one year. IRB approval will expire on **June 28, 2019**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

This study may be selected for a post approval review by the IRB. The review will include an in person meeting with members of the IRB to verify that study activities are consistent with the approved protocol and to review signed consent forms and other study related records.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB, maintain proper documentation of study records and promptly report to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,
Leah Stoiber

Leah Stoiber
IRB Administrator

Appendix F

Study Recruitment Flyer

Scleroderma Study

I'm a Registered Nurse who is interested in knowing about what your experience is like living with systemic scleroderma

I will be conducting two sets of interviews:

- Women who have been living with systemic scleroderma for 1-6 years
- Women who have been living with systemic scleroderma for 7 or more years

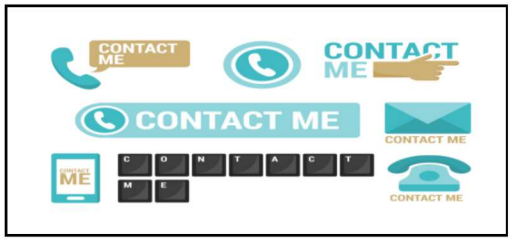
If you join this study, I will record an interview with you. I will ask you questions about living with scleroderma and ask you to share your story.

I am willing to meet for a phone interview

This study may help nurses better understand and take care of people with scleroderma.

If interested in learning more about the study please contact me

Donald Miller, MSN, RN
Email: ddmiller@uwm.edu
Phone: (414) 704-7497



UNIVERSITY of WISCONSIN
UWMILWAUKEE
College of Nursing

You will receive a gift card for participating in this study

CURRICULUM VITAE

EDUCATION:

Degree: Master of Science in Nursing (Education focus)
RN-MSN Program
Walden University- Minneapolis, MN
Matriculation: September 2005
Graduation: September 2008

Degree: Master of Science in Psychology (Health Psychology focus)
Walden University- Minneapolis, MN
Matriculated: September 1999
Graduated: May 28, 2004
Thesis: The Bariatric Patient: Psychopathology and Successful Strategies Toward a Positive Outcome

Degree: Associate Degree in Nursing
Cardinal Stritch University- Milwaukee, Wisconsin
Licensure: Registered Nurse - State of Wisconsin
Matriculated: January, 1996
Graduated: December, 1998

Degree: Bachelor of Arts-Psychology
St. Mary's University San Antonio, Texas
Area of Special Interest: Neuropsychology
Matriculated: August, 1991
Graduated: May, 1994

Additional Course work: University of Wisconsin-Milwaukee
Area of Interest: Psychology and Biology

ACADEMIC EXPERIENCE:

Marquette University
Milwaukee, WI
College of Nursing
Academic Rank: Instructor
Full Time Faculty: August, 2018-Present
Part Time Faculty: October, 2017-May 2018

Cardinal Stritch University
Milwaukee, WI
Ruth S. Coleman College of Nursing and Health Sciences
Academic Rank: Assistant Professor: 2008-June, 2018
Full Time Faculty: September 2008-June, 2018
Adjunct Clinical Instructor
Spring Semester: January, 2008- to May, 2008

Bryant & Stratton College
Milwaukee, WI
Adjunct Instructor: Medical Assistant Program & Nursing Program
Summer Semester 2005-Januarary 2008

Carroll College
Waukesha, WI
Adjunct Instructor: Department of Psychology
Academic Year 2004-2005

University of Wisconsin-Milwaukee School of Nursing (Covenant Healthcare Systems, Inc.)
Adjunct Instructor: Clinical Nursing Instructor
Fall Semester 2003

MEMBERSHIP IN LEARNED SOCIETIES AND PROFESSIONAL ORGANIZATIONS:

National Society of Collegiate Scholars
University of Wisconsin-Milwaukee Chapter
Inducted: Fall 2012

Sigma Theta Tau International—Eta Nu Chapter
Inducted: November, 2011

Emerging Scholars Network
Midwest Nursing Research Society (MNRS)
Member: 2016-present.

Midwest Nursing Research Society (MNRS)
Member: 2011-present.

American Nurses Association (Wisconsin Nurses Association)
Member: 2019-present

Council for the Advancement of Nursing Science (CANS)
Member: Student membership: Fall, 2018-present

Doctoral Student Nursing Organization (DSNO)
University of Wisconsin-Milwaukee

September 2010-Present
Office held: Vice President 2010-2012

American Association of Colleges of Nursing – Academic Membership
Member: 2008-Present

The National League for Nursing – Academic Membership.
Member: 2007-Present

Alpha Sigma Lambda- Eta Psi Chapter:
National Honor Society for Academic Excellence
Inducted: Spring, 1994

PSI-CHI: The National Honor Society in Psychology
Inducted: April, 1992

The National Dean's List
Inducted: 1992

PRESENTATIONS:

Poster:
Miller, D., Mosack, K.E. (May 2014). Medication beliefs of HIV positive individuals: A thematic analysis. Poster presentation at the Building Bridges Nursing Research conference at Marquette University, Milwaukee, WI.

Heron, E.A., Lenihan, M. and **Miller, D**. (1994). Cognitive function in air force boxers [abstract]. *Proceedings of the 14 Biennial Applied Behavioral Symposium*. Colorado Springs, CO: United States Air Force Academy.

PUBLICATIONS:

Doering, J.J., Sims, D.A., & **Miller, D.D.** (2017). How postpartum women with depressive symptoms manage sleep disruption and fatigue. *Research in Nursing and Health, 40,* 132-142. doi:10.1002/nur.21782

Hartlep, N., Ecker, M., **Miller, D**., Whitmore, K. (2013). Asian Pacific American college freshmen: Attitudes toward the abolishment of affirmative action in college admissions. *Critical Questions in Education, 4*(1). http://education.missouristate.edu/AcadEd/75532.htm

Miller, D., (2012). Faculty mentoring: Priceless. *Journal of Professional Nursing*. Sept-Oct; 28 (5). *Letter to the Editor.*

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Charge RN
Advanced to Clinical RN III
December 1998-June 2011

Position held: Clinical Educator
September, 2001-April, 2003