

SELF-DIRECTED LEARNING AND THE LUPUS PATIENT: USING ADULT
EDUCATION STRATEGIES TO ACTIVELY COPE WITH CHRONIC
ILLNESS

by

Kristin Brittain

A Dissertation Submitted to the Faculty of

the College of Education

In Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

Florida Atlantic University

Boca Raton,

August 2016

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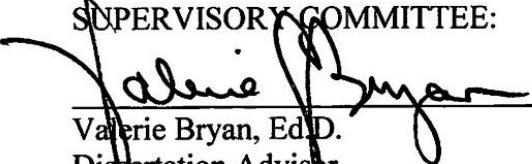
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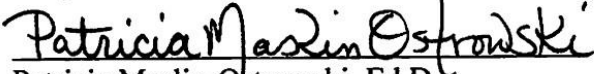
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This dissertation was prepared under the direction of the candidate's dissertation advisor, Dr. Valerie Bryan, Department of Educational Leadership and Research Methodology, and has been approved by the members of her supervisory committee. It was submitted to the faculty of the College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

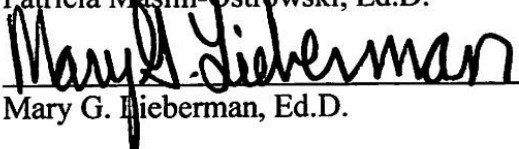
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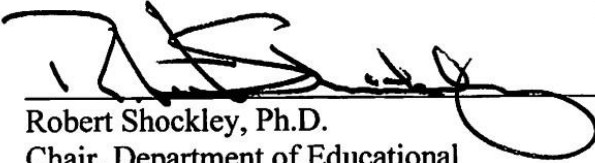
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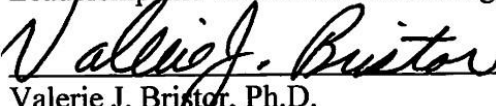
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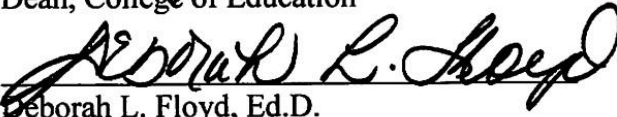
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ACKNOWLEDGEMENTS

Without the support, mentorship, and encouragement of my dissertation committee this work would not have been possible. I would like to thank Dr. Valerie Bryan first and foremost. Thank you for not only being the Chair of my committee, but for also serving as an example of what it means to be a strong, intelligent woman. You have functioned as my mentor, advisor, confidant, and friend, and I cannot thank you enough for your guidance and support. You have had a profound impact on me. Thank you for allowing me to “grow up” in this program and to become the person that I am today. Dr. John D. Morris, Dr. Mary Lieberman, and Dr. Patricia Maslin-Ostrowski, thank you for your expertise and advice throughout this process. Dr. Lucy and Paul Guglielmino, thank you for your continued support and encouragement.

I would also like to acknowledge and thank the incredible people I have met throughout this journey. A special thanks to Dr. Elizabeth Swann, Dr. Rivka Felsher, and Fran Kamin, always present in spirit, thank you for enriching my life. Also, to the FAU MacArthur staff and faculty, your encouragement and support have been instrumental to me. I can't have imagined a better place to work and spend my time for the past five years.

The Lupus Foundation of America and the Lupus Foundation of Florida, thank you for accommodating my requests and allowing me to utilize your organization's resources. Further, to all of the participants of this study and my fellow Lupus Warriors, thank you for opening yourself up, sharing your stories, and providing your time.

Most importantly, I would like to recognize and thank my family for their love and support throughout this journey. Sue and Michael, my mother and father, Lauren and Michael, my sister and brother, without you I would be nothing. Thank you for always believing in me, even when I didn't. To Tony Dicuia, thank you for your endless support and keeping me sane and laughing throughout this process. Your love and encouragement have meant the world to me. Thank you for always being on my team. I couldn't have asked for anyone better.

As a final thank you, and in an unconventional twist, Finley and Small Cat, you were by my side every step of the way. The two of you have been closer to my work than any human, mostly because you were usually laying on top of it.

ABSTRACT

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Title: Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness
Institution: Florida Atlantic University
Dissertation Advisor: Dr. Valerie Bryan
Degree: Doctor of Philosophy
Year: 2016

The purpose of this study was 1) to examine the significance of a patient's active or passive role in terms of his/her health management; 2) to determine if a relationship exists between one's *active* and *passive* scores and his/her self-directed learning readiness, and 3) to identify if his/her view of one's self as a patient (when diagnosed with a chronic disease) impacted his/her own personal health management.

Utilizing the quantitative analysis of *The Self-Directed Learning Readiness Scale* and the *Vanderbilt Pain Management Inventory*, 81 individuals' descriptive statistics were analyzed. Self-directed learning was found to positively influence an individual's ability to be an *active patient*. The moderated demographic characteristics of age, ethnicity, education level, and gender did not have a direct relationship between self-directed learning readiness and active/passive coping groups.

Further, it was established that the majority of the participants within the study, 83.75%, considered themselves an *active* patient managing their lupus diagnosis. However, 16.25% of the participants did not believe that they were actively managing their illness.

Self-directed learning characteristics were examined through the responses to an open-ended question. The two most prevalent themes pertained to active coping and control. Characteristics of self-directed learning readiness appeared predominant amongst the responses, particularly *goal-orientation* and *accepting responsibility for learning*. Minimal themes regarding *planning* and *enjoying learning* were provided within the data.

These characteristics were identified throughout the study in hopes of further research and program implementations that will help to develop leadership abilities and activity levels of self-health management in chronically ill patients. This will enable lupus patients to have a more positive outcome, it will help them successfully manage their own health, and it will improve their overall quality of life.

DEDICATION

I am so grateful to have had such amazing women in my life to serve as examples of what it means to be a strong, intelligent woman. I would like to dedicate this dissertation to Sue Brittain and Lauren Kleen. Not only have you taught me what strength is, but most importantly, unconditional love and laughter. Thank you for giving me the confidence and belief that has enabled me throughout not only this process, but every aspect of my life. I could not have done it without you. Bottom line, without your provocation, encouragement, and occasional abuse, I would be nowhere.

Also, to my niece and nephew, Olivia and Chase, my head and my heart are forever grateful for your presence and unwavering love. You two inspire me to be a better person and make the world a better place. Love you, always.

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I. INTRODUCTION

Due to the current complexity of the United States health care system, patients are increasingly being asked to take more responsibility for their own self-care. Even for the most educated individual, this can be a challenging task. In fact, it is estimated that 40 million Americans have limited health-related literacy (Williams, Davis, Parker, & Weiss, 2002). Nearly half of all American adults, 90 million people, have difficulty understanding and acting upon health information (Institute of Medicine, 2004). The majority of health information is disseminated through patient education information, insurance forms, advertisements, and other complicated medical materials. The information available is considered by many to be complicated in nature. In fact, even individuals with strong literacy skills may struggle with accessing and understanding health related information.

As an individual's health changes in response to aging, wellness management, or disease, having access and the ability to understand health related materials is crucial to successfully managing one's health; which therefore, directly affects one's quality of life. Furthermore, in order to correctly manage one's disease, individuals have to go beyond the previously held notions in which the patient is more or less a passive participant in his or her treatment and wellness plan. This means rescinding the belief, that has been so prevalent and considered the "norm" within the medical field that upheld the traditional hierarchy between physician and patient. Within the context of this situation, the

doctors dictate to their patients rather than establishing a partnership with them. However, context is constantly changing, especially in today's dynamic healthcare field. Patients are now progressively expected to establish a mutual partnership with his or her health management team. The newly established relationship model means that patients are more responsible for their self-healthcare management.

Clearly, health professionals and patients have different worldviews. As a result, professionals often target health education at the wrong place. Self-management begins with the patient's perceived problems, not with what health professionals think the patient needs to learn (Lorig, 2001). Thus, this new dynamic is establishing the need for better understanding of patient material, a high ability for patients to discern what is considered quality information, and becoming more autonomous in leading one's self throughout his/her health management and wellness journey. Research shows that there is a relationship between taking the *initiative* and *responsibility* and *self-management* that effects the outcome for the patient (Champagne, 2001, p. 46). In fact, "a key component in the prevention and management of all forms of chronic illness is education" (Champagne, 2001, p. 46).

Despite the fact that today's medical and technological advances far exceed former practices, the obstacles that individuals now face concerning healthcare have become more exacerbating than ever before. The health information barrier is detrimental to individuals trying to successfully navigate their lives. Further, due to the massive and devastating rise in chronic illnesses,

health has become at the forefront of many national, political, and personal concerns. Lorig (2001) articulates:

To put this into a public policy context, in the traditional view, the health care system in the United States provides primary, secondary, and tertiary care. But in fact, these represent only 20 percent of health care. About 80 percent of health care today is self-care, care that individuals do for themselves... that is why the whole area of self-care, or self-management, has become a very important health policy issue. (p. 36)

To illustrate, consider the fact that, “the major causes of mortality and morbidity in the United States have shifted from infectious diseases to chronic illnesses, and in the next 25 years this shift will occur worldwide” (Funk & Tornquist, 2001, p. 4). Furthermore, when chronic illness is generally thought of, the majority imagine elderly individuals in the later portion of their lives that develop age-related illness. However, it is important to note that, despite popular opinion, not just the elderly suffer from chronic conditions. In fact, “thirty-one percent of children under the age of 18 years” (Funk & Tornquist, 2001, p. 3) are assumed to be affected by chronic conditions; and, “for over a third of these children, severity of the condition results in limitation of activity” (Funk & Tornquist, 2001, p. 3). As the devastating impact of the current epidemic of diagnosis of chronic illnesses upsurge, the shattering effect of chronic disease is becoming more apparent and recognized by not just the medical community, but the greater society in which the escalation is effecting.

This notion is further intensified when considering the fact that many individuals who are diagnosed with one chronic illness will more than likely develop other illnesses as well. Moreover, this fact is exaggerated through the sometimes devastating nature that health related problems can cause within one's life.

Therefore, not only is the connection between education and health management becoming increasingly more popular, but awareness regarding the crucial understanding of the unpredictable nature of chronic illness needs to be considered as well. Especially considering the broad spectrum in which chronic disease can occur, the many different symptoms that these illnesses can create, and the multiple organ systems that they can effect. Funk and Tornquist (2001) characterize chronic disease by stating:

Chronic illnesses are caused by pathological changes in the body that are nonreversible, permanent, or leave residual disability; they may be characterized by period of recurrence and remission; and they generally require extended periods of supervision, observation, care, and rehabilitation. (p. 4)

By emphasizing and understanding the permanency of chronic disease the need to be at the forefront of one's health management is crucial to successfully manage the specific illness and symptoms which may occur. Due to the fact that a central charge in life is caring for one's own health, taking all of these factors into account is beyond important.

Because one's health directly impacts his/her quality of life, at this point, the exploration into the underlining connection between health management and education is dire. That is because "chronic illnesses have a major impact on all aspects of a person's life—physical, psychological, familial, social, vocational, and economic" (Funk & Tornquist, 2001, p. 4). These impacts are accompanied by sometimes extreme consequences. Funk and Tornquist (2001) explains, "they may result in impaired functioning, limitations in self-care and activities of daily living, loss of independence, pain and discomfort, emotional problems, and self-image changes" (p. 4).

As the diagnosis of chronic disease continues to rise, so must the public's knowledge regarding these diseases. It has already been determined by many researchers that learning is essential to health (Hill, 2011). Further, adult learning aids individuals through changing physical abilities, medical conditions, lifestyle changes, or social conditions resulting from health related issues (Hill & Ziegahn, 2010). Therefore, adult learning empowers the individual to become a participant rather than an observer in her own treatment. The notion of being an active patient, an individual who is engaged with health related materials and his/her own self-care, is crucial in order to successfully manage one's own health. That means going beyond the health information barrier, pushing past the unpredictable nature of chronic illness, and actively establishing one's health as a priority. As Lorig (2001) so simply states, "you cannot not manage" when one is diagnosed with a chronic health disorder (p. 36). Further, Lorig (2001) suggests:

A person with a chronic illness has to manage the disease. He or she can manage the disease by staying home and becoming totally unfunctional, a burden on society and the family, or the person can be proactive and manage the disease and continue to lead a full and happy life. The difference between those two has very little to do with the disease process. It has to do with self-management. (p. 36)

To further explicate the importance of the connection between health and education and the dire level of significance that managing one's own health is at, the current epidemic of emerging chronic diseases cannot be overlooked or understated. According to the Center for Strategic International Studies (CSIS) (2013), "rates of non-communicable or chronic disease continue to increase dramatically in all countries (industrialized, middle income, low income), surpassing infections as a disease burden among adults" (para. 1). In fact, in 2002, 60 % of the 56 million deaths worldwide were somehow related to chronic disease (Center for Strategic International Studies, 2013). The leading chronic disease problems are: cardiovascular diseases (including strokes), cancer, chronic lung disease (including asthma), and diabetes. Population aging, urbanization, economic development, and "globalization" of consumer markets help drive the increases in occurrence of major chronic disease. According to the Center for Strategic International Studies (2013), "population aging allows more people to live to the age when these diseases become manifest" (para. 11). As individuals are living longer and healthier lives, due to all of these factors and more, the diagnosis of chronic disease has reached epidemic proportions. It is important to

consider that “the term chronic illness comes from the Latin word *chronicus*, meaning ‘for the time’” (Champagne, 2001, p. 43). As one medical practitioner so eloquently reflects on the root word of “chronic illness,” she states:

For those of us who do not have a chronic illness, I suspect it is only “for the time.” For those who are chronically ill, however, it is for the time remaining—ever present. The challenge is to create a functional fulfilling life with chronic illness. (Champagne, 2001, p. 43)

Self-health management, behavioral, and lifestyle factors are directly effecting individual’s quality of life and health and wellness management by directly relating to the causality of these illnesses.

Though the dire effects of the chronic illnesses already mentioned, such as cancer and heart disease, cannot be overlooked, there are other illnesses that directly impact millions of people, during any stage of life, but receive less consideration. These diseases receive less attention from the medical community—which directly affects research funding, public education, and awareness campaigns. So, how about the less innocuous chronic diseases; the ailments that get little global attention, and therefore, are less recognized and researched, but still reek as much havoc? Lupus is one such chronic disease.

Lupus is an autoimmune, chronic disease in which the body’s immune system becomes hyperactive and attacks normal, healthy tissue. Once one experience symptoms of lupus, he or she will have lupus for life. It is a chronic illness because it is incurable. Varying stages and activity level of the disease results in a multitude of unpredictable symptoms such as inflammation, swelling,

and damage to joints, skin, kidneys, blood, the heart, and lungs. However, lupus can go beyond these major systems and cause damage to any part of the body. According to Dr. Robert Lahita and Dr. Robert Phillips, world renowned medical practitioners and lupus researchers:

There is no more difficult disease to diagnose, understand, or treat than the disease called systemic lupus erythematosus... It may also be because the disease can present itself to both physicians and patients in mysterious ways, throwing off the track, leading them to think of other more common illnesses, and eluding standard diagnostic methods. Whatever the reason, lupus is complex and problematic. (2014, p. x)

Although it is not nearly as known throughout the world as other chronic diseases, such as cancer, lupus is a formidable disorder. According to the Lupus Foundation of America, the disease is commonly described as an autoimmune disorder that has multi-organ and system involvement that affects 1.5 million Americans and at least five million people worldwide.

Both men and women can be diagnosed with lupus; however, it is more predominant in women. In fact, 90 percent of individuals diagnosed with the disease are women. Lupus is most prevalent amongst African-Americans. However, the disease also occurs more frequently in Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians, and other Pacific Islanders than in Caucasian women (Lahita & Phillips, 2014). Lupus is not considered to be hereditary in the traditional sense, but there seems to be an uncharted genetic link that has not been uncovered yet.

Skin, joints, and internal organs can all be affected (a major organ, such as the heart, lungs, kidneys, or brain is affected in nearly half of the individuals diagnosed with Systemic lupus (Crosta, 2008). Symptoms vary greatly amongst patients, and many mimic other diseases or present themselves as overlapping diseases. Signs and symptoms of lupus include painful, stiff, or arthritic joints (hands, knees, ankles, etc.), epidermal issues (including rashes, skin lesions, painful nodules, and swollen glands), kidney involvement is also common (accompanied by (possible) renal failure), mental and cognitive dysfunction (including the well documented “lupus fog”), pulmonary involvement (comprising embolism, chest pain, endocarditis, myocarditis, blood clots, shortness of breath, and even pleurisy), frequent sickness, sensitivity to sun and light, and swelling, amongst many others.

Lupus takes place when the immune system is unable to differentiate between antigens and healthy tissue. This leads the immune system to direct antibodies against the healthy tissue - not just antigens - causing swelling, pain, and tissue damage. Lupus can attack any part of the body’s major systems.

There are three types of lupus: systemic lupus erythematosus (SLE, simply referred to as *lupus*), discoid (only effecting the skin), drug-induced, and in small percentages it can also occur within a neonatal state and possibly be outgrown during early childhood development (Crosta, 2008). Five million people throughout the world are thought to have some form of lupus (Lupus Foundation of America, 2013). The Lupus Foundation of America (2013) estimates that there are at least 1.5 million Americans currently living with lupus, with more than

16,000 new cases reported annually. However, it is believed that the actual number of people living with lupus may be higher, but due to the fact that there have not been any large-scale studies to reflect the true number of individuals living with lupus in the U.S., the figures reported are not accurate. Further, these numbers only account for individuals that have been hospitalized due to lupus. The organizations, such as The Lupus Foundation of America, The Lupus Research Institute, and Alliance for Lupus Research, and even the government's Center for Disease Control (CDC) and National Institute of Health (NIH), gather statistics through information reported from U.S. hospitals. So, even these statistics are complicated because the actual number of individuals hospitalized will never accurately reflect the amount of persons currently living with the disease. Which is because most people are hospitalized due to symptoms and complications of lupus (such as pain, fatigue, etc.), and not the actual illness. Further, the majority of documentation and medical processes that are reported to insurances agencies list differing causes in order for specific coverage options for the patients.

“Lupus makes the body turn against what it is designed to protect” (Lahita & Phillips, 2014, p. 4). There are many symptoms of lupus. It is hard to diagnosis; in fact, it is called *the great imitator* because the symptoms that a person with lupus may experience often resemble several other indicators that are common in, or mimic, other chronic autoimmune diseases (Lupus Foundation of America, 2013). Lupus is further described as a formidable disease because of the varying and unpredictable nature of the illness itself. No two patients will experience the

disease in the same way. One might have similar and relatable symptoms, but these can occur at any time, on a spectrum of severity, and lasting different lengths of time. To illustrate:

Lupus is a chronic disease but can have acute episodes. As a chronic disease, lupus often has a slow onset, and it is ongoing and incurable. The immune system—unable to rid itself of what is perceived as foreign substance—continues to react against the ‘foreign tissue.’ This can be a significant problem, lasting for quite a while—possibly up to many months—and can be accompanied by signs and symptoms of other chronic illnesses. But a patient can experience acute episodes, times when symptoms can worsen in immediate, abrupt, and occasionally severe ways. These acute manifestations, known as flares, can often occur this way, even in those who had the disease for many years. (Lahita & Phillips, 2014, p. 2)

Because lupus can affect so many different organs, a wide range of symptoms can occur, appear and disappear at any time, and affect many different bodily systems—sometimes impacting multiple systems at one time. Due to the varying nature of lupus, it is important for patients to become active, self-directed learners in order to increase their quality of life and management of the disease.

Since learning is central to health, health decisions, and self-care, adult educators’ insights regarding lifelong, self-directed learning (SDL) are critical in helping adults learn about their disease and make informed decisions. This revelation is especially important to those diagnosed with chronic illnesses because these diseases are a lifelong

battle, accompanied by a sometimes erratic and unpredictable future. As one progresses with lupus, experiencing the disease as symptoms wax and wane, becoming more invested and self-directed in one's own health management is essential to successfully living with the disease.

With the complicated nature of the existing healthcare system, and prevalent occurrence of chronic illness, new measures need to be taken to properly address the present issues. According to Lorig (2001), due to the fact that, "neither the public health nor the medical model can [appropriately] deal with chronic disease," (p. 35) and that it is "the number one demand on the system," (p. 35) the public health model cannot solve this problem. Thus, the exploration between health and adult learning principles is vital.

Research in the field of self-directed learning (SDL) has found that SDL occurs in a wide variety of contexts, can be a response to a personal need, and may be conducted independently or collaboratively (Guglielmino, 2008). Changes in health, diagnosis of a disease, or the desire for improved health may trigger a need for learning. This need has been understood to perhaps evolve into a transformative learning experience as adults adapt to their new roles as lupus patients.

When faced with a new medical challenge, adults will turn to health providers, friends, family, support groups, the internet, and written material seeking out knowledge. Many of these resources are easily accessible, however in some cases, this is the pivotal point toward potential barriers to learning. Further, the notion of being a self-directed learner is critical in developing the proper coping mechanisms to aid sufferers in properly managing/coping with their healthcare. As individuals navigate the often times difficult world of chronic illness, this idea becomes especially true when considering the varying

nature of lupus. “Lupus is a disease demanding much attention, and a delicate balance exists between patient and doctor” (Lahita & Phillips, 2014, p. 275). Thus, the connection between properly managing one’s own health, education, and self-directed learning needs to be addressed.

Consequently, this research study presented documentation of self-directed learning and health education present in a group of individuals, with a positive diagnosis of lupus, actively involved in their own health management. Managing chronic illness is a “day-to-day” responsibility. As Lorig (2001) so accurately describes this process, she puts into context the situation facing patients today, in this position, “the patients ...manage their disease on a day-to-day basis. In chronic illness, when people fall into the river we need to be able to help them learn how to swim—quickly” (p. 36).

Problem

“In these times of rapid change one thing remains the same: The existence of chronic illness;” (Corbin, 2001, p. 1) across all age groups, ethnicities, socioeconomic levels, and genders. The rise of chronic illness is a problem that needs to be addressed. Especially with the expected rise in the overall presence of disease. It is believed that:

By the year 2030, it is projected that 150 million Americans will have one or more chronic conditions. Of that number, 42 million will have activity or limitations restricting their ability to work and live independently [...] At the same time, because of advances in modern medicine, persons with chronic conditions are living longer and more productive lives. Addressing

their varied health care needs is one of the major challenges facing the present health care delivery system. (Corbin, 2001, p. 1)

Furthermore, chronic illness is a global problem that affects every person, at the individual and societal level, whether one is the actual person diagnosed with the disorder. To explicate further, there are major economic impacts specifically related to chronic disease; these include (a) higher health care costs; (b) lost productivity due to illness; (c) disability and death among the working age population; and (d) the need to replace these lost workers. Currently, according to The Partnership to Fight Chronic Disease (2013), out of every dollar spent on health care in the U.S., 86 cents goes toward treating patients with chronic disease. Further, over the next 15 years, it is expected that 80 percent of the United States population alone will experience one or more chronic conditions. The costs will escalate to more than \$42 trillion in medical care spending and losses in employment productivity (The Partnership to Fight Chronic Disease, 2013). However, some of these expenditures can be avoided by addressing the epidemic properly. In fact, it is believed that just by incorporating healthier behaviors a vast amount of physical and monetary means can be improved upon.

According to The Partnership to Fight Chronic Disease (2013):

Over the next 15 years, adopting healthy behaviors, developing better treatments, and improving access to high quality care for chronic disease would result in 16 million saved lives, \$6.3 trillion in savings, and 169 million avoided cases. (p. 2)

By looking at health related research recently produced, there is an indication that the role of learning and an individual's health care management needs to be explored further. This is especially true considering the devastating and varying nature of chronic illness, and more specifically, that of lupus. Furthermore, the literature that is available (Covic, Adamson, & Hough, 2007; Frank, 1999; Gilbert, 2012; Hill, 2011; Hill & Zieghan, 2010; Lahita & Phillips, 2014) shows that being a better informed patient positively impacts health care and wellness. However, if the information is provided to the patient using medical jargon, the individual patient may not value the information or understand what he/she is being told. Without appropriate or valued information, and the comprehension of that information, an individual may make choices that could increase the time to achieve wellness or the individual could even make life-threatening choices.

Not only is research on the correlation between the role of learning and health management needed, but further investigations regarding the relationship between lupus and the patient are also just as necessary. According to the Lupus Research Institute (LRI), lupus is one of America's least recognized major diseases. The dichotomy between the number of individuals suffering from lupus and the knowledge regarding the disease is grossly expanding.

The LRI states, "while lupus is widespread, awareness and accurate knowledge about it is lacking" (Lupus Research Institute, "Advocacy," 2016, para. 6). In fact, it wasn't until 2011 when the first lupus-specific drug therapy was approved, and it is the first therapy produced solely for lupus in over 50 years (Lupus Foundation of America,

2013). Considering the fact that rheumatologist agree that lupus is not an easy disease to treat because of its varying nature and person specific symptoms, the questions surrounding the illness are only being multiplied. Lahita and Phillips (2014) states that *ironically* lupus has “gotten more complex, not less, over the years. New knowledge about the immune system and its workings has led to other autoimmune diseases being added to the roster of problems and resolutions” (p. x).

Furthermore, the ability to accurately self-manage one’s own healthcare is vital in successfully navigating the confusing channels that persons with chronic illnesses experience. Studies of the chronically ill demonstrate that successful self-management skills decrease symptoms, improves function, and improves self-advocacy (Champagne, 2001). Many researchers now advise against the previous model of healthcare management. The traditional process of healthcare management and delivery, that was founded and consisted of physician directed care, complicated medical materials, and passive patient involvement, is now no longer the preferred method. For example, Champagne (2001), states:

The whole question of self-management and who is in charge has to be very, very clear. The notion of personal responsibility for health has become fashionable—which can also trivialize it. Nevertheless, for health professionals to be successful, or for a person with chronic illness to live well, a passive aggressive approach, with the provider aggressive and the patient passive, simply does not work. Individuals and their families must take responsibility for managing their risk factors of their chronic illness. To do so, patients and families need information and help with management skills and behavioral change. (p. 45-46)

Moreover, studies have also documented a higher occurrence of depression and other negative experiences/feelings/thoughts within patients whom experience chronic pain, prolonged flares, fatigue, and many other experiences and symptoms that lupus patients suffer from. Whiteman (2015) explains:

But it is not just the physical symptoms that can make day-to-day life difficult for people with lupus; the disease can have a negative impact on mental health, too. [...] around 90% of people with lupus experience anxiety as a result of the condition and around 85% feel depressed. [...] Lupus can make a person feel tired and weak, causing them to withdraw from social activities, which can make them feel isolated. Another challenge with lupus is that the disease is often "invisible," which can make it hard for others to understand what people with lupus are going through. (para. 11)

As Higgins and Leibowitz (2001) determine, "illness or disability may or may not threaten a person's self-theory of being a 'good' person, but it will typically threaten his or her sense of being in control" (p. 29) This notion is supported by Winters (2001) who affirms that a major source of stress for individuals suffering with chronic illness is uncertainty, and this uncertainty impacts the patients' ability to cope. The high levels of uncertainty experienced by persons diagnosed with lupus stems from "the perceived ambiguity of the illness, lack of information about the diagnosis and seriousness of the illness, complex treatment options and a complex system of care, and the unpredictability of the course of the disease" (Winters, 2001, p. 161). The "uncertainty" experienced by the patient directly impacts his/her psychologically. In turn, the psychological impact of a patient can directly impact one physically as well as the level of severity of the symptoms

experienced. In fact, “some 67 percent of people with lupus have psychological abnormalities (Lahita & Phillips, 2014, p. 271). Furthermore, Dr. Lahita and Dr. Philips (2014), conferred that depression and anxiety can actually cause a flare of the disease. For these reasons, and many more, the ability to be an active patient and to properly cope with this disease needs to be explored.

One of the “largest issues facing America: how can we prevent disease and live gracefully with chronic health conditions” (Frank, 1999, p. vii-ix) that affects so many? Researchers believe, “By advancing the theory of and science of coping” (Frank, 1999, p. vii-ix). Coping goes beyond the idea of basic survival mechanisms. In order to lead a life of quality, especially when diagnosed with a chronic illness, active, positive coping is essential. Positive, active coping “is a response aimed at diminishing the physical, emotional, and psychological burden that is linked to stressful events and daily hassles” (Snyder & Dinoff, 1999, p. 5). This negative psychological burden consists of adverse impacts resulting from disease activity, psychological effects, and poor healthcare management. In order to combat the negative consequences experienced by many chronic illness sufferers, positive, active coping is needed. Further, “the effectiveness of the coping strategy rests on its ability to reduce immediate distress, as well as to contribute to more long-term outcomes such as psychological well-being or disease status” (Snyder & Dinoff, 1999, p. 5). So not only does proper coping have an immediate, supportive effect, but there are also long term outcomes and responses that positively contribute to future disease and wellness management.

However, there is a severe lack of research concerning these specific areas. While efforts are being made to find new ways to diagnose and treat lupus, there is one factor

that continues to hamper progress: lack of awareness and knowledge about the disease. In fact, “More than 70% of people in the U.S. aged 18-34 have never heard of lupus or do not know anything about it other than the name, which researchers and health care providers across the country believe is a concern” (Whiteman, 2015, para. 17). Again, due to lupus affecting so many individuals, and with the rise of chronic disease in general, the development of lupus-specific research is crucial, if not mandatory, especially concerning the areas of health management, education, and coping.

Purpose of the Study

The purpose of this study was 1) to examine the significance, if any, of a patient’s active or passive role in terms of his/her health management; 2) to determine if a relationship exists between his/her active and passive scores and his/her self-directed learning readiness, and 3) to identify if his/her view of one’s self as a patient (when diagnosed with a chronic disease) impacted his/her own personal health management.

This research endeavor was a quantitative analysis of two specific instruments measuring a patient’s self-directed learning readiness and his/her ability to manage and/or cope with the illness. In particular, the patient’s approaches to learning and personal characteristics were analyzed and compared to the characteristics associated with the elements of self-directed learning. Furthermore, the researcher has identified self-directed learning elements that are essential for patients actively managing/coping with his/her chronic illness. These characteristics are identified throughout this study in hopes of further research and program implementations that will help to develop leadership abilities and activity levels of self-health management in chronically ill patients. This will

enable lupus patients to have a more positive outcome, it will help them successfully manage his/her own health, and it will improve their overall quality of life.

Research Questions

1. What is the relationship, if any, between the *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients?
2. What is the relationship amongst the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score?

Hypotheses

1. There will be a statistically significant relationship in the scores of self-directed learning readiness if a patient is defined by the *Vanderbilt Pain Management Inventory* as being an active versus passive patient.
2. There will be a statistically significant relationship between the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score.
 - a. Age will significantly affect the relationship.
 - b. Education will significantly affect the relationship.
 - c. Ethnicity will significantly affect the relationship
 - d. Gender will significantly affect the relationship.

Significance of the Study

This research study provides knowledge and information to an area that does not receive adequate attention. With the increase of chronic disease, the complex nature of

the American health care system, and the push for individuals to become more dynamic and self-sufficient in their health management, research into the field of self-directed learning combined with health management is essential to successfully navigating one's own health. As the health care system becomes more and more muddled, community driven health-related educational programs are becoming increasingly more imperative. Furthermore, additional explorations into the disease of lupus itself is vital due to the lack of knowledge and research currently available. As one of the most widespread chronic diseases, lupus demands further attention and serious investigations.

Definitions

Health literacy: the degree to which an individual has the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Centers for Disease Control and Prevention, 2011).

Chronic disease: Chronic diseases are complex and varied in terms of their nature, how they are caused, and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability, and they are lifelong ailments. Features common to most chronic diseases include:

- complex causality, with multiple factors leading to their onset
- a long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications
- associated functional impairment or disability (Australian Government's Department of Health, 2012).

Lupus: Systemic lupus erythematosus (SLE) is “an autoimmune disease in which the body's immune system mistakenly attacks healthy tissue. It can affect the skin, joints, kidneys, brain, and other organs. The underlying cause of autoimmune diseases is not fully known” (U.S. National Library of Medicine, 2013, para 1). Specifically, the cause of lupus is unidentified, currently there are no cures, and there are various treatment options available. Furthermore, the evolution of the disease is highly variable; disease activity ranges from minor complaints to death.

Self-directed learning: The ability of an individual to actively identify a learning need, develop a plan of action, seek resources, implement learning strategies, and evaluate progress. Self-directed learning readiness determines characterizations of self-directed learning as measured by scores from the *Self-Directed Learning Readiness Scale*. Highly scored SDLRS's indicate a higher level of readiness to engage in self-directed learning.

Self-directed learning characteristics: Characteristics include: (a) goal oriented; (b) accepts responsibility for learning; (c) takes initiative in learning; (d) independence; (e) desire to learn/change; (f) self-confident; (g) persistence in learning; (h) self-discipline; (I) high degree of curiosity; (j) views problems as challenges and not obstacles; (k) use of basic study skills; (l) develop a plan for competing work; and, (m) organize time/pace of learning.

Self-health management: An individual's ability to engage in self and preventive health care. There has not been a concrete conceptualization of the term “self-management” for healthcare purposes, therefore, the overarching concept is (a) self-management aims at helping patients to maintain a wellness in their foreground perspective; (b) self-management healthcare is based on the patient's perceived problems; (c) one of the

largest problems amongst self-management in health care is integrating it into the health care system.

Active patients: Patients whom are actively engaged in their health management and treatment process. These individuals use active coping strategies and aim to control the pain or continue to function in spite of it.

Passive patients: Patients whom are not actively engaged in their health management and treatment processes. These individuals are instructed/directed in healthcare practices instead of becoming part of the health management team. They're not seen as in control of their environment, and the strategies to control the pain experienced is passed over to others.

Coping: the cognitive and behavioral attempts to manage environmental and internal demands and conflicts. Coping with pain can include adaptive or maladaptive strategies that may or may not act as a function as moderators of pain adjustment.

Active Coping: the uses of adaptive strategies employed by individuals to control their levels of pain or function despite of it.

Passive Coping: the uses of maladaptive strategies, for example, strategies in which individuals relinquish control of their pain, allow themselves to be consumed by pain, or adversely affected by pain.

Internal locus of control: An individual that believes that he or she can influence events and their outcomes and sees one's self as in control of such.

External locus of control: An individual that blames outside and uncontrollable forces as cause for everything, including success and failure.

Self-efficacy: An individual's belief in his or her capacity to perform behaviors and exert control.

Patient Leader: An individual that is engaged within the active dimensions of coping and healthcare management and whom see outcomes dictated by their own behaviors. With this mindset, patients are perceived as innovators and entrepreneurs of their own health management.

Quality of life: The spectrum on which one successfully manages his/her health and how that management affects one's life. Quality of life ranges from high to low and can fluctuate depending upon disease activity and management.

Healthy aging: Successfully combating age-related body degeneration and disease occurrence while maintaining a high quality of life.

Rheumatism: an umbrella term that is used to describe any disease that affects pain, joints, muscles, or fibrous tissue that is often chronic and accompanied by pain and inflammation.

Rheumatology: the study of rheumatic disorders.

Rheumatologist: An individual who studied and received further training in the diagnosis and treatment of rheumatic, musculoskeletal and systemic autoimmune diseases.

Biologic medication: genetically engineered proteins derived from human genes that are designed to inhibit, stimulate, or block specific components of the immune system.

NSAID: nonsteroidal anti-inflammatory drugs, agents, medicines.

Delimitations

Participation in this study is delimited to patients who (a) have had a positive diagnosis of lupus; (b) located throughout the state of Florida; (c) attend lupus support

group meetings provided by the Lupus Foundation of America or the Lupus Foundation of Florida.

Limitations

There are several limitations to this study. Patient limitations include: (a) the nature of self-reporting; (b) mental health issues that are sometimes present in patients of chronic illnesses and how it affects their activity and engagement level with their health management at different times throughout their disease progression/activity levels; (c) disease activity level and how it affects the patient's engagement in his/her health management at the time. Furthermore, it has been determined that the patients attending support groups, versus the patients whom do not, already exhibit some degree of self-directedness and this should be kept in consideration when looking at the results.

Researcher limitations

Chronic illness affects many Americans, regardless of age, gender, or ethnicity. Therefore, it is not inconceivable that what sparks interest in specific research topics are personal experiences and histories. Research begins with one question, but what leads to that question is just as important to the study and results of such. People have been known to say, *without suffering there would be no compassion*. Consequently, it is important to reflect on the researcher's own personal narrative in consideration of this study. Researcher limitations include a possible present bias due to the researcher's current health status, a positive diagnosis of lupus and rheumatoid arthritis.

Contrary to popular belief, lupus can affect anyone, at any age. Chronic illness doesn't discriminate. To illustrate, beginning at age eight, I began to exhibit symptoms of lupus; painful, swollen, and stiff joints, odd lesions, chest pains, migraines, fatigue, etc..

These symptoms continued to progress as my health continued to decline. During this time, I went to many doctors, ranging from a myriad of specialist, as well as multiple types of physical therapies, psychologist, and children's hospitals. Eventually, I relied on a wheelchair and could not physically attend school. It wasn't until around the age of twelve that I received some sort of answers. I said, *some sort* because even after being treated for lupus and a rheumatoid arthritis cross-over, the cause of my symptoms was never truly definitive. Even now, *the great imitator* is called into question, despite the presence of positive bloodwork results and physical symptoms.

Before I got better, I got worse. New symptoms developed, my life, and consequently, my family's life, was consumed with an *invisible*, autoimmune illness that no one seemed to understand. Doctors were perplexed. Medications failed. I struggled. Life continued this way for several more years. Odd, unknown symptoms, pain, medication, doctor appointments. The cycle never ended, until the illness went into remission. At that time, high school passed with no interruptions from the lupus. Besides experiencing more extreme cases of normal ailments (mono, sinus infections, etc.) I was *okay*. Life went on.

However, little did I know that, *okay*, wasn't going to last. During my freshman year of college I began experiencing painful symptoms again. Once more, I was seeking answers and specialist. After many years of remission, I found myself back in the cycle of doctors and prescriptions. Symptoms began again—some old, some new. At this time, I began a new medication regiment. I tried many different types of medication, ranging from self-injection chemotherapies, biologic infusions (genetically engineered proteins derived from human genes that are designed to inhibit, stimulate, or block specific

components of the immune system), NSAIDS (nonsteroidal anti-inflammatory drugs, agents, medicines), steroids, etc.. This continued until I found a medical *cocktail* that seemed to lessen my symptoms. Little did I know how adversely corrosive some of these medications would eventually become. What seemed to save my life at that time is now the cause of what has unapologetically *destroyed* my body. Apparently, everything comes at a cost—even health.

I graduated from college, earned my bachelor's degree, and began graduate school. During my tenure at Florida Atlantic University I earned a Master's degree and, with the completion of this study, my PhD. However, during this timeframe, lupus reared its ugly head again. Surgeries on both knees, both eyes, a gallbladder removed, kidney issues, a heart attack (on my 25th birthday), more drug and pain management trial and errors (more errors than trials), new symptoms, and the development of other simultaneous occurring chronic, autoimmune diseases, once again, ruled my life. Before this, I thought my penance was served. I never anticipated that I would have to relive my previous experience. Moreover, I never considered that I would have to re-experience it in a more extreme form. Prior to this, I thought I knew what it meant to *cope* with a chronic disease. To put it in laymen's terms, *been there, done that*.

But, I was wrong. This seemingly never-ending flare up commanded new questions and discoveries. As I once again embarked on the intense search for health, I questioned how to best deal with this reoccurrence. How do I take charge of my life, which seemed to once again, belong to my illness? Lupus is an incurable disease. The only way to manage and treat lupus is through medication and coping. But, how is that done?

As I mentioned prior, research begins with one question; and, what leads to that question is just as important to the investigation. Again, that is why it is important to note, in this specific study, the researcher's current health status. Due to my experience with lupus and chronic disease, I saw a need. It took me years to acquire a diagnosis. There are very few research studies conducted on the disease. I sought answers and found none. This led to even more unrequited questions; which eventually led to the search for my own answers.

The researcher's personal narrative and identification with the specific sample used in this study must be considered when evaluating the results and interpretations. Possible bias needs to be recognized and taken into consideration. However, this does not necessarily have to be considered a limitation because it allowed the researcher to gain access to this marginalized group. Due to the presence of lupus the researcher was able to infiltrate the sample and allow for a total immersive experience. Thus, the participants were more eager and willing to share their experiences and express their feelings with an individual who could truly empathize. Further, through using a quantitative process and a priori method of establishing themes/codes, measures were taken to avoid perpetuating bias.

Framework

The framework for the study, *Self-Directed Learning and the Lupus Patient: Using Adult Learning Strategies to Actively Cope with Chronic Illness*, overall, is continually enclosed in a constant, flexible construct, consisting of health status, societal systems, and barriers, which affects all individuals at multiple levels. Subsequently, the assumptions and context are specific to each individual (moderated by one's unstable and

ever-changing disease activity level and fluctuating self-directed learning readiness abilities).

The foundation of the study is comprised of the interaction between the patient's ability to actively and positively or passively manage/cope with the diagnosis of lupus and how one's levels of self-directed learning readiness directly affects that interaction (see Figure 1). This collaboration between self-health management and education, more specifically self-directed and lifelong learning, occurs in the broader context of the varying nature of lupus, the ever-increasing complexity of the current healthcare system, and the possible barriers to understanding health related materials and information.

The study's major construct that consist of the broad context already established (i.e. the varying nature of lupus, the healthcare system, and information barriers) is comprised of several specific layers that are particular to each individual. This paradigm is not static. When examining this study and the structure that frames it, it is important to keep in consideration the ever-changing possibilities exhibited between the longevity, order, and occurrence of each dimension. Specifically disease activity and individual context can moderate the configuration. Nevertheless, in the prototypical, and favored progression of the framework, active participation within one's health and wellness management concludes in successful patient leadership.

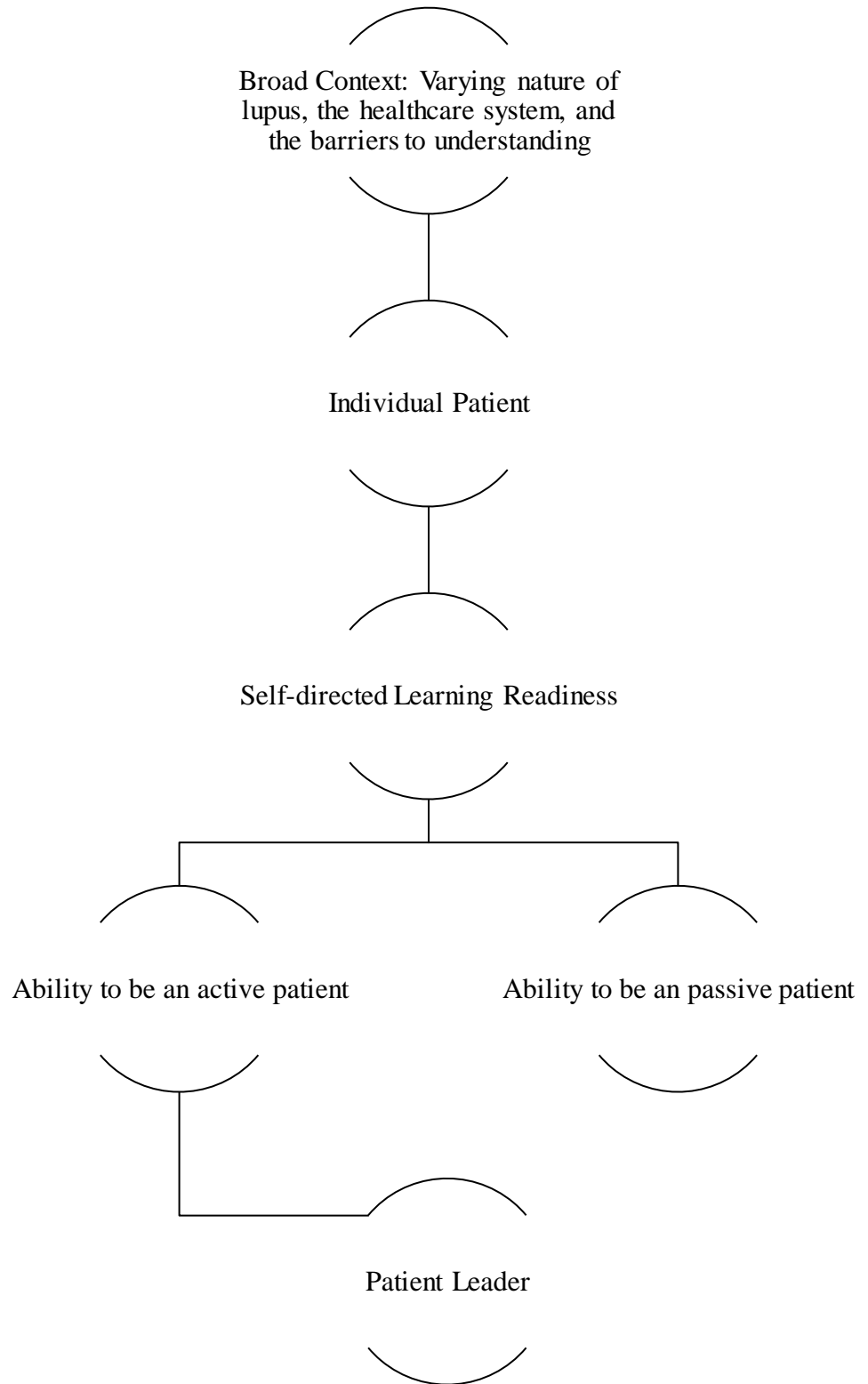


Figure 1. Kristin Brittain's Conceptual Framework.

Chapter Summary

Within this chapter the research study, *Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness*, was introduced. The researcher created a framework for the study. The constructs of the framework presented the connection and importance between healthcare management and learning within a broader context, such as the complex nature of the healthcare system, the level of understanding of medical information, health literacy, the rise of chronic illness, and the lack of awareness regarding lupus. The fact that the development of chronic illness is an epidemic, and that people are now experiencing more than one chronic illness, directly relates to research, awareness, and solutions available. In particular, lupus and coping abilities are explored in depth and the lack of research specific to lupus was illustrated.

The problem the study addressed, the two research questions that guided this study, and hypothesis were also posed. The limitations and delimitations to the study were conferred. In addition, in order to provide more clarity and to be as transparent as possible, the role of the researcher, in particular the researcher's past histories and potential bias due to a positive lupus diagnosis, were also explored. Further, the significance of the study to the greater field of adult learning and health was elucidated on.

II. REVIEW OF THE LITERATURE

As previously established in the introduction to this study, a central charge in life, if not the most important responsibility, is caring for one's own health. Health is not static, but ever changing in response to aging, wellness management, or disease. Researchers agree that learning is essential to health (Hill, 2011).

Explicitly, adult learning aids individuals through changing physical abilities, medical conditions, lifestyle changes or social conditions resulting from health related issues (Hill & Ziegahn, 2010). Adult learning further empowers the individual to become a participant rather than an observer in his/her own treatment. As today's health care system becomes more and more complex, and chronic disease diagnosis continues to rise at extreme rates, it is imperative for patients to become more self-directed in nature and assume ownership over their own bodies; and this specifically includes managing their health care. In order to become an autonomous, self-directed patient, learners need to begin seeing themselves as their own advocate and participant within the team of doctors that lupus patients generally have. This is a representation of *patient as an advocate* and *patient leader* acting as a derivative of self-directed learning.

Further, research suggests, "Individuals living with lupus are becoming their own best advocates as they become more knowledgeable about the disease" (Lahita & Phillips, 2014, p. 279). Again, this theory will only come into fruition if the previously upheld hierarchy between doctor and patient is abolished. Thus, establishing a more autonomous learner and patient—which is so necessary in today's health climate. This

also means that if patients are becoming their own advocates, more research and information needs to be available as resources. Patients cannot accurately self-manage their health, treatment, or wellness plans if there is not enough research regarding their specific disease. Again, this is another illustration emphasizing the significance and impact of a study of this nature.

Not only is the emerging concept of developing and nurturing *patient advocates* or *patient leaders* significant to every individual, regardless of health status, it is, however, especially significant to those who are battling chronic illness. Due to the emerging reliance of health management being transferred to the patient, rather than solely being dependent on the physician to improve or sustain one's health, the investigation between self-directedness in learning and the ability to be an active participant in one's health is vital. Literature shows that context clearly dictates the learning situation, tools and resources used, as well as the level of the learner's understanding.

As Merriam and Caffarella (1999) state, "adult learning does not occur in a vacuum" (p. 22). In fact, learning is context driven. Catherine A. Hansman further illustrates:

in contrast to psychological and behavioral understandings of learning, sociocultural models posit that learning is not something that happens, or is just inside the head, but instead is shaped by the context, culture, and tools in the learning situation. (2011, p. 45)

Thus, the presences of a positive lupus diagnosis creates not only a need for learning and the chance to become more autonomous, but it also creates an environment

and context in which learning occurs outside of formal settings, utilizing a variety of patient resources, as well as by creating a partnership between patient and healthcare provider or specialist.

To further illustrate, the diagnosis of a chronic illness, flare-up of a reoccurring or new symptom, as well as deciding upon treatment and prevention options are context driven situations in which an active patient will utilize a myriad of resources to attain and comprehend information regarding his/her health management. As levels of complexity within the healthcare field escalate and the amount of people being diagnosed with chronic illnesses rise, researchers are becoming more aware of the importance of studying self-health management.

By looking at recent studies and publications regarding barriers to health management and learning, the rise of chronic disease and the implications of more frequent diagnosis, lupus research and its evolution to current practices, awareness, and understanding of the disease, and self-directed learning, the dire need for further research is explicitly clear. Further, looking into the connection between learning and a person's ability to be an active patient is crucial to understanding the nature of individuals' who are successfully managing his/her own healthcare.

A patient's discernment regarding his/her coping and self-management abilities directly correspond to his/her belief regarding one's locus of control and positive management of lupus symptoms—despite level of severity. By further investigating the characteristics that create the temperament of an active, self-directed patient learner, once understood, can be disseminated to improve the quality of life of other lupus sufferers as well as individuals experiencing similar chronic ailments. Additionally, when this

understanding is garnered and the learning that occurs within a self-health management context is further explored, informal and formal learning situations, community education programs, lectures, seminars, and support groups created to support active, patient learners can be expounded upon with more success. Consequently, leading to the establishment of highly self-directed, motivated, and health conscious patient-leaders. This not only lifts the burden from the physician and the overly distressed healthcare system, but it also transforms and motivates the patient. Subsequently, creating a person capable of actively coping with the varying and sometimes devastating nature that is specific to the chronic disease of lupus.

In order to appreciate the depth of this study it is imperative to truly understand the varying and complex nature of chronic illness. Lupus is a dynamic disease that has innumerable levels of symptom activity and severity throughout a patient's lifetime. Corbin (2001), in order to explicate this notion, created a trajectory consisting of disease phases. These phases can occur at any point and does not necessarily have to follow the order in which it is written:

Trajectory is defined as a course of illness over time, plus the actions taken by patients, families, and health professionals to manage or shape that course. [...] Over time, the course of chronic conditions tends to vary, unless the condition is very mild and invariable. Symptoms increase and decrease; physiological status changes. To capture the dynamic and changing character of chronic conditions, the concept of phasing has been added to trajectory. (Corbin, 2001, p. 3)

Nine different trajectory phases (see Table 1) have been identified (Corbin, 2001, p. 3):

Table 1

Trajectory Phases of Disease Occurrence

Phase	Definition	Goal of management
Pretrajectory	Genetic factors or lifestyle behaviors that place an individual or community at risk for development of a chronic condition	Prevent onset of chronic illness
Trajectory onset	Appearance of noticeable symptoms, includes period of diagnostic workup and announcement of biographical limbo as persons begins to discover and cope with implications of diagnosis	Form appropriate trajectory projection and scheme
Stable	Illness course and symptoms are under control. Biography and everyday life activities are being managed within limitations of illness. Illness management centers in the home	Maintain stability of illness, biography, and everyday life activities
Unstable	Period of inability to keep symptoms under control or reactivation of illness. Biographical disruption and difficulty in carrying out every day .life activities. Adjustments being made in regimen with care usually taking place at home	Return to stable
Acute	Severe and unrelieved symptoms or the development of illness complications necessitating hospitalization or bed rest to bring illness course under control. Biography and everyday life activates temporarily placed on hold or drastically cut back.	Bring illness under control and resume normal biography and everyday life activities

Table 1 Continued

Phase	Definition	Goal of management
Crisis	Critical or life-threatening situations requiring emergency treatment or care. Biography and everyday life activities suspended until crisis passes.	Remove life threat
Comeback	A gradual return to an acceptable way of life within limits imposed by disability or illness. Involves physical healing, limitations stretches through rehabilitative procedures, psychosocial coming to terms, and biographical reengagement with adjustments in everyday life activities	Set in motion and keep going the trajectory projection and scheme
Downward	Illness course characterized by rapid or gradual physical decline accompanied by increasing disability or difficulty in controlling symptoms. Requires biographical adjustment and alterations in everyday life activity with each major downward step	To adapt to increasing disability with each major downward turn.
Dying	Final days or weeks before death. Characterized by gradual or rapid shutting down of body processes, biographical disengagement and closure, and relinquishment of everyday life interest and activities.	To bring closure, let go, and die peacefully.

This trajectory encompasses not only the physical burden of chronic disease, but it also takes into account the mental aspects and how it affects individuals close to the patient.

Wiener and Dodd (2001) state:

Trajectory refers not only to the physical unfolding of a disease, but to the total organization of work done over the course of the disease—together with the impact of consequences, of the disease and its work exert on the lives of the people involved, namely, patients, family and health professionals. (p. 184)

Barriers to Health Management

Due to the need of an active, self-directed patient to have access to proper medical resources, the barriers to health management must be understood. A recent proliferation of peer reviewed articles addressing health promotion, barriers, and health literacy indicates a need to further explore the role of learning and an individual's self and preventive health care. The overarching goals of the *Healthy People 2020*, determined by the U.S. Department of Health and Human Services, include:

1. Attain high quality, longer lives free of preventable disease, disability, injury, and premature death.
2. Achieve health equity, eliminate disparities, and improve the health of all groups.
3. Create social and physical environments that promote good health for all.
4. Promote quality of life, healthy development, and healthy behaviors across all life stages. (U.S. Department of Health and Human Services, 2011)

All of these goals can be better served if the barriers preventing the improvement of health management are eliminated.

Due to the ever increasing expectations for adults to take responsibility for their own health care management, many individuals experience difficulties undertaking such a task. The insistence placed on the patients in today's healthcare system is a stark

contrast to the past. The technology that is now available to the general public help make health materials and medical information widely available. Prior to today's advanced technology, the majority of individuals were limited to the medical information and complicated forms in which they appeared in. Previously, medical information and resources were directed towards medical professionals rather than patients in need.

Take for instance medical information's unfamiliar vocabulary and concepts. How an individual comprehends these terms and concepts is identified as health literacy. *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) defines health literacy as the degree to which an individual has the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Centers for Disease Control and Prevention, 2011, p. 1). Research indicates that being a health literate person means that one is more informed and better able to make intelligent decisions regarding his/her health care and lifestyle choices. The Institute of Medicine indicates health literacy as "when the expectations, preferences, and skills of the individuals seeking health information and services meet the expectations, preferences, and skills of those providing [the] information and services" (2004, p. 2). Part of evolving into an active patient involves the emergence of health literate patients through the establishment of these skills.

Many current studies have addressed the impact of low health literacy on an individual's choice of treatment regimens and the response to those regimens. The Institute of Medicine (2004) identified literacy skills as the strongest predictor of an individual's health status from the following demographics: age, income, literacy skills, employment status, education level, and racial or ethnic group. Based on current

information, 90 million people “have difficulty understanding and using health information” (Institute of Medicine, 2004, para. 1).

Individuals need information regarding their own role in their health care. Extensive literature is available regarding how being a better informed patient positively impacts his/her own health care, but if that information is given in medical vernacular, the individual patient may not value the information or understand what she is being told. Without appropriate or valued information, and the comprehension of that information, an individual may make choices that could increase the time to achieve wellness. Or even worse, the individual could make life-threatening choices.

When patients receive a diagnosis or treatment plan, they are often presented information that could inform and aid them to make intelligent decisions about their own care, but often the information is presented in clouded or obtuse language, with charts or graphs that confuse even the most educated user. Medical jargon used by physicians often requires extensive medical vocabulary training. This predominate use of “med-speak” distances the patient from their freedom to make individual health choices. These individuals are at a disadvantage that results in a lack of understanding of what role they are to play in this setting.

Literature on health literacy demonstrates the complex issues associated with the language or treatment processes for the novice patient and the resulting impact on the treatment process. It is estimated that 40 million Americans have limited literacy (Williams et al., 2002). This translates to approximately one-third of the population (36%) is estimated to have basic or below basic health literacy (Martin et al., 2009). Additionally, the Institute of Medicine found that 90 million American adults may lack

the necessary skills to effectively use the U.S. health care system (Institute of Medicine, 2004).

Moreover, with the emergence of the Affordable Care Act, the introduction of government subsidies, new laws regarding the necessity of health insurance, and the lack of transparency between those in need and the services available, the amount of individuals who cannot successfully navigate the U.S. health care system is only expected to escalate. Those who suffer from chronic disease are among these statistics.

In 2009 the Calgary Charter on Health Literacy defined health literacy as the skills and competencies that all people develop to seek out, comprehend, evaluate, communicate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life (Coleman et al., 2009). It is essential that the patient and the caregiver share these concepts in order to ensure the best quality of life, regardless of the presence of disease.

Several factors have been identified as contributing to an individual's level of health literacy. They are as listed: (a) efficacy (Parker & Kreps, 2005; Parikh, Parker, Nurss, Backer & Williams, 1996); (b) age (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Gazmararian, Curran, Parker, Bernhart, & DeBuono, 2005; Matzke, 2007; Schechter & Lynch, 2010; Williams et al., 2002); (c) cognitive ability (Baker, Gazmararian, Sudano, & Patterson, 2000; Baker et al., 2002; Matzke, 2007; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005); (d) income (Matzke, 2007); (e) ethnicity (Matzke, 2007); (f) geographic location (Matzke, 2007); (g) education level (Matzke, 2007); (h) shame (Parker & Kreps, 2005; Parikh et al., 1996); (i) happiness (Angner, Miller, Ray, Saag, & Allison, 2010); (j) fear (Parikh et al., 1996;

Parker & Kreps, 2005); (k) physical abilities such as hearing (Porth, 2007; Saeed & Rasden, 1994) or vision (Porth, 2007; Solomon & Donnenfeld, 2003); (l) social trust (Schechter & Lynch, 2010); and (m) unwillingness to disclose information about personal health status to health professional (Schechter & Lynch, 2010). All of these associated issues play a role in the treatment processes for the novice patient.

Furthermore, these factors impact the health management abilities throughout one's life, regardless of disease presence or activity. These factors not only highly impact those suffering from chronic illness, but they also affect individuals whom may just have a minor cold, infection, or broken bone. Without the proper medical information and understanding, those simple medical situations can become extreme problems if not dealt with properly. Minor colds can turn into chronic bronchitis or a respiratory infection—affecting the lungs or the surrounding errors of the heart. Infections can become life threatening if not treated with the proper antibiotics. Broken bones can heal improperly if not looked after in the correct way—resulting in lifelong, chronic pain and bone or joint deformities.

Another barrier to health management that directly contradicts health-promoting opportunities is any “perception” that corresponds to the unavailability, inconvenience, or difficulty of reaching a particular “health-promoting option” (Stuifbergen, 2001, p. 79). Financial resources are also related to health behaviors and their outcomes. Stuifbergen (2001) confirms that “low-income people, regardless of ethnicity, have a rate of disability, measured as activity limitations, twice that of whites and greater than all other ethnic groups” (p. 79). Furthermore, barriers may arise from people's internal cognitions, from significant others, and from the environment. Existing literature documents barriers

to health care services for both disabled and nondisabled persons; they include distance, cost, availability of services, and aspects of the provider-consumer relationship (Stuifbergen, 2001).

Individual factors are not the only barriers toward the treatment process. Factors within the health system, such as compliance with complicated medication regimes (Matzke, 2007) influence the successfulness of the treatment process as well. This is important to note considering that in 2007, “there [were] 11,000 types of medications available in the United States ... than compared to several hundred available in the 1960s” (as cited in Matzke, 2007, p. 22). The number of medications have only risen. With the saturation of the pharmaceutical market comes the confusion surrounding which medication to use, which pill has the least amount of side effects, and which types of medication are cost prohibited. These questions only further complicate the treatment process.

The amount of time physicians spend with the patient is another factor (Davidoff, 1997). To illustrate, “Patients are experiencing shorter office visits and not having adequate time to communicate with their physicians” (as cited in Matzke, 2007, p. 4). Physicians assume that patients should undertake a higher level of self-care (Williams et al., 2002) and are able to use multiple health care choices (Matzke, 2007). However, this is not the case. Not every patient has developed the necessary communication skills, health literacy levels, and autonomy to adequately compensate for the lack of interaction between patient and physician.

The resulting inadequacies can lead to: (a) higher medical costs (Weiss et al., 2005); (b) increased hospitalization (Baker, Parker, Williams, Clark, & Nurss, 1997;

Baker et al., 2002; Baker, Parker, Williams, & Clark, 1998; Kalichman & Rompa, 2000; Williams et al., 2002); (c) poorer health outcomes (Matzke, 2007); (d) poorer health knowledge (Matzke, 2007; Williams et al., 2002); (e) lack of awareness amongst individuals of health services available (Davis, Meldrum, Tippy, Weiss, & Williams, 1996); (f) individuals whom are less likely to participate in health prevention activities (Matzke, 2007); and (g) individuals whom are less likely to participate in health screenings (Bennett et al., 1998; Lindau, Tomori, McCarville, & Bennett, 2001). These factors can lead to late entry into the health care system by the patient, and thus allowing advanced stages of disease to occur before even seeking treatment.

Due to these factors established as health management barriers, and the rise in complexity of the healthcare system, the access and use of healthcare and resources available become compromised. Which directly impacts the health and quality of life of the patient. Furthermore, if patients do in fact take advantage of the healthcare opportunities available to them, patients whom utilized a specific treatment process, may have difficulty with discharge instructions or follow up appointments (Spandorfer, Karras, Hughes, & Caputo, 1995; Williams et al., 1995; Wilson & McLemore, 1997).

Matzke (2007) cites studies that found patients with low health literacy to have: (a) poor recall and comprehension of health care advice and instructions; (b) poor understanding of diseases; and (c) poor problem-solving skills. Issues of noncompliance with the plan of care (Gazmararian et al., 2005; Williams, Baker, Honig, Lee & Nowlan, 1998; Williams, Baker, Parker, & Nurss, 1998) and medication adherence are of special concern when looking at chronic disease management (Matzke, 2007; Williams et al., 1995) as well.

Furthermore, in some cases, medical practitioners dismiss chronically ill individuals and label them as noncompliant. Kleisinger (2003) reports that patients often exhibit behaviors that interfere with their own treatment for a variety of reasons. It is assumed that this can result from the patient possibly being unable to understand what is communicated by the health professional due to education level, language fluency, or even dementia or cognitive difficulties experienced as symptoms of the illness. In most cases, the health practitioner fails to address those possibilities. Noncompliance can also result from (a) the patient's culture or personal beliefs may cause the patient to be non-receptive, and again, the medical practitioner takes minimal time to unearth the issues; (b) the patient may be noncompliant because of fear, psychological conditions, or other coping mechanisms to deal with his or her illness; (c) patients may enjoy "being ill" to avoid other things such as an unpleasant work setting or home situation; or (d) patients may have secondary issues that make noncompliance of less importance to them than some of their primary issues such as alcohol or drug dependency or the effects of the addiction.

The dismissal of chronically ill individuals and labeling them as "noncompliant" is a prevalent issue amongst chronic disease sufferers. Especially those persons diagnosed with a chronic, autoimmune disease whom undergo specific mistreatment from practitioners within the medical community. The sometimes stark dichotomy between the outside appearance of chronic, autoimmune disease sufferers, compared to the turmoil and internal destruction that is being inflicted within the body by the disease, creates misunderstandings between the physician and patient. Due to the *invisibility* and lack of outward manifestations of lupus, patients might not be determined as "sick enough" or

their symptoms might be more commonly dismissed. This misunderstanding can result in a lack of consideration of a patient's symptoms. In turn, this can cause a reluctance in chronic, autoimmune patients to pursue a treatment process. In fact, "a normal patient waits five to ten years to be diagnosed [with lupus]" (Lahita & Phillips, 2014, p. 63). Many lupus patients must wade through multiple misdiagnosis and dismissals from healthcare professionals before they even have the chance to become "noncompliant."

Many patients note feelings of frustration because of the lack of understanding from others around them. The fact that the disease is often *invisible* is the issue. "You may face many who doubt the veracity of your illness, believing it is all in your head. This can be extremely painful, frustrating, causing anger and resentment," notes non-profit foundation *Molly's Fund: Fighting Lupus* spokesperson (as cited in Whiteman, 2015, para. 9). In order to successfully address the issue of creating an acceptable quality of life, "individuals diagnosed with a chronic disease must adapt to the experience of living with a long-term, incurable illness that imposes limitations on function" (Hawthorne, 2001, p. 76). This is especially important considering that many descriptive studies of chronically ill individuals have related to changing roles and identities after the manifestation of a chronic illness. This is because "increasing severity of illness [is linked] to decreased sexual activity, severe restrictions in recreation and leisure activities, limitations in instrumental nurturing roles for homemakers, and reduced labor-market activity and income" (Stuifbergen, 2001, p. 81).

The correlation between a negative quality of life due to chronic disease activity needs to be recognized in order for new learning and improvement to take place. The

ability for learning to take place in conjunction with healthcare directly relates to self-healthcare management and the ability to be an active patient and lifelong learner.

Self-Healthcare Management and the Learner

Previously, the notion of self-healthcare management simply meant someone who was an active participant in the treatment of one's own disease. The term is used widely, and according to Lorig and Holman (2003), it was used mainly when referring to patient education programs for people suffering from chronic disease (p.1). Lorig and Holman also stated that there has not been a concrete conceptualization of the term "self-management" for healthcare purposes, so they proposed the following:

Traditionally, researchers have thought of chronic illness as having a disease course that waxes and wanes due largely to physiologic changes. Recently Patterson pointed out that patients have shifting perspectives on their illness. She suggested that persons with chronic illness sometime have illness in the psychological foreground and sometimes wellness. These shifting perspectives are in part due to the waxing and waning of the disease but are also due to psychological factors. Within this paradigm, self-management aims at helping patients to maintain a wellness in their foreground perspective. (2003, p. 1)

Self-management healthcare is then based on the patient's perceived problems. One of the largest problems amongst self-management in health care is integrating it into the system itself. The current climate of the healthcare system is ill prepared to assimilate self-management into the mainstream medical culture. Changes are needed at many levels. In order to address the biggest challenge, Hill (2001) states, "to prevent and manage chronic illness, the challenge now is to incorporate the science beyond biology"

(p. 12) and “to translate the potential into reality, to move from intention to action. To do this, we need to move from information to behavior” (p. 13).

Health management and learning can be framed within the creation of the constructionist theory with the intention of understanding the learning process that ultimately affects personal health. Hein (1991) states that the term refers to the idea that learners construct knowledge for themselves, individually and socially, and that the learner creates the meaning while he/she is engaged with learning itself. Thus, through an individual’s engagement with reality, he/she will construct meaning; and this process applies to health and wellness plans as well. This notion is further explicated by the belief that “all knowledge and all meaningful reality is contingent upon human practice, being constructed through interaction between human beings and their worlds, and developed and transmitted within their social context” (Crotty, 2003, p. 42, as cited in Valente, 2011, para. 6).

In this sense, in order for the learning process to truly be taken advantage of to its fullest capacity by the patient, learning must be integrated within his/her health and wellness plans. The patient must be actively engaged within his/her healthcare management. This type of necessary engagement can take place at the self-directed level, on one’s own, or in conjunction with the physician or team of physicians. A team of specialists is usually required for individuals suffering from chronic illnesses because patients generally need to consult multiple specialists for separately occurring symptoms. (Specifically in lupus, “it is the symptoms that are being treated and not the real disease, since the actual cause is still unknown” (Lahita & Phillips, 2014, p. 33) so there are multiple physicians needed.) The type of learning that was previously mentioned can

also take place in a group setting, such as a support group, which can be virtually or physically based.

To further exemplify the association and need for learning and healthcare management, Valente (2011) asserts, “Few other issues in life require such diligence as understanding and making decisions [then those] affecting one’s personal health” (para. 7). Throughout many stages of life, occurring within any context, individuals can be heard elucidating on the importance of good health. A familiar ideal that the majority of human beings uphold is that *without health, you have nothing*.

Chronically ill individuals must manage a wide variety of disease-related, “intrapersonal, and environmental demands” (Stuifbergen, 2001, p. 83) to maintain their quality of life, specifically by adopting coping and behavioral strategies. However, as important as it is for patients to take charge over their own healthcare, there are some barriers that thwart the process. A caveat to the connection between learning and healthcare management previously illustrated is that sometimes a patient who actively seeks out health related information, and whom is determined to be a part of his/her healthcare and wellness plan, can be found vexing to healthcare providers.

Patients that take the initiative to find, understand, and appraise information received from the medical team can be viewed by the medical team as *bothersome* and *time consuming*. Many times the physicians who determine that patients’ eagerness to be actively involved in the treatment of their chronic illness as “difficult,” are the type of healthcare provider that upholds the former, traditional model. These physicians generally believe in healthcare management as a dictatorship, rather than viewing it as a team approach with the patient at the center of the wellness plan. Furthermore, “behavior

change” for the chronically ill poses additional challenges beyond disease prevention and health promotion. This can represent a challenge because many symptoms experienced by lupus patients effects behavioral capabilities. “With chronic illness, a patient has to manage a complex regime and has to do so under the burden of suffering, often with threats to physical and interpersonal function” (Champagne, 2001, p. 48).

According to Weiss (2001), “the root of the problem, often termed nonadherence, is a concern not only for health care providers, but also for clients and the nation” (p. 173). Medical researchers define adherence as the level in which a patient’s behavior collaborates with the physicians. “Health promoting behaviors involve continuing behavioral, cognitive, and emotional efforts to sustain and improve health and well-being” (Stuifbergen, Seraphine, & Roberts, 2001, p. 195). The term self-care suggests this.

The way that people form perceptions and make decisions about self-care could be an important missing link in understanding adherence and nonadherence (Weiss, 2001, p. 174). Stuifbergen et al., (2001) confer that few studies have examined the health promotion needs or behaviors of persons with chronic, disabling conditions. “Although health-promoting behaviors may not change the course of illness or the barriers and resources existing in an individual’s life, [however] they may influence the individual’s response to such conditions (Stuifbergen et al., 2001, p. 196).

If a patient wants to assume autonomy over his/her healthcare management, it is important for him or her to be able do so. “Self-management is crucial to positive outcomes, as is self-efficacy” (Champagne, 2001, p. 51). This is especially true of individuals suffering from chronic illnesses such as lupus, because “The object of treating

the patient is to prevent flares that are immune rejections of his or her own cells and tissues. If lupus is left untreated, death can result” (Lahita & Phillips, 2014, p. 49). Therefore, if the proper healthcare management isn’t implemented, dire consequences can be the outcome.

Coping as a Healthcare Management Strategy

Although the majority of research studies pertaining to chronic illness and pain have been focused upon the physical, there has been a recent interest into the cognitive and behavioral milieu of the patient concerning treatment outcomes. According to psychologist, Robert Frank, changes in healthcare delivery, based off of the “critical revolution in the delivery of healthcare,” (as cited in Snyder, 1999, p. v) has not only resulted from new economic and quality concerns surrounding healthcare services and patient access; but it has also, “led to a new emphasis on outcome measures” (p. v). Frank continues to divulge the importance of coping and healthcare management, “Now the prevention of disease is essential. Fundamental to prevention of disease is a comprehensive understanding of coping and its implications for psychological and physical health” (as cited in Snyder, 1999, p. vii).

For many, the ability to cope, whether that means exercising specific behaviors physically or cognitively, can mean the difference between successfully navigating his/her health. Being a sufferer of chronic pain, or diagnosed with a chronic illness involving pain, can be a world-changing experience. “One of the largest issues facing Americans: how can we prevent disease and live gracefully with chronic health conditions that will affect as many as 100 Americans? By advancing the theory of and science of coping,” (Snyder & Dinoff, 1999, p. 5) asserts well known psychologists and

researchers, C.R. Snyder and Beth I. Dinoff. How one adapts to the diagnosis can dramatically impact his/her levels of functioning, quality of life, and overall health management. “One general fact repeatedly implicated as influencing adjustment to chronic illness has been coping, defined as the person’s cognitive and behavioral efforts to manage the stress-producing aspects of the illness” (Smith, Wallston, Dwyer, & Dowdy, 1997, p. 11).

Increasingly, there has been an emphasis on the psychology of the positive, and a growing focus within the academic and public interests on the spectrum of emotion and coping (Frank, 1999). In addition, the importance of coping to both healthy functioning and “positive emotions” (Frank, 1999, p. vi) and “the consequences of deficiencies in coping,” (Frank, 1999, p. vi) which have been previously ignored, is under new investigation.

Snyder and Dinoff (1999) contend that coping is basic to survival, and furthermore, they posit that coping directly effects the quality and constructive meaning of one’s life. “Coping is defined as constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person” (Redeker, 2001, p. 17). According to Lazarus and Folkman (1984), coping is neither a personality style nor a defense mechanism, but a dynamic process between the persona and the environment. “Personal characteristics of age, education, and gender have been suggested as correlates of coping. Consistent relationships, however, have not been found” (Redeker, 2001, p. 18).

However, due to specific roles that men and women are expected to perform and are assigned, there seems to be significance amongst the different ways that gender

effects coping abilities. Hawthorne (2001) asserts that there is a difference between the ways in which men and women cope: “Data revealed significant problems with caregiver recognition and access to care. Barriers to care may also exist due to women’s traditional subordinate role in American society and their gender specific interactive skills” (p. 36). This impression is important to note due to the great prevalence of lupus diagnosis in women over men.

Additionally, positively coping with chronic illness is a factor associated with individuals whom successfully adapt to their condition (Smith et al., 1997). Pain coping strategies may act as moderators of adjustments to the patient’s response to chronic pain (Brown, Nicassio, & Wallston, 1989). Furthermore, “Coping strategies used by chronic pain patients have been associated with psychological adjustment as well as treatment outcome” (Turek, Norris, & Tan, 1995, p. 455). Moreover, coping has been traditionally classified according to the specific type of strategy employed, which is either emotion or problem focused. The majority of the coping process can directly relate to how the chronically ill experience and interpret their initial diagnosis and responses.

To illustrate, Snyder and Dinoff (1999) state:

many elements that are common to the coping process, including appraising the event as stressful (i.e., stretching one’s immediate resources), feeling rather overwhelmed (i.e., stress as a mediator between environment and behavior), and behaviorally responding to specific components of an event (i.e. coping, including with both emotions and events). (p. 4)

correspond to the process a person undergoes when first diagnosed with a chronic illness. Due to the complicated nature of lupus, this notion is especially associated with those diagnosed with this specific disease because:

The diagnosis of lupus is not a simple process. There is no test designed specifically to detect lupus. Because the symptoms of lupus are so similar to those of other disease, patients must undergo many tests, and many criteria must be met before a patient is diagnosed with lupus. (Lahita & Phillips, 2014, p. 63)

In conservative numbers, it commonly takes a person an average of four years to before one is officially diagnosed with lupus. If ever receiving an official diagnosis. This in itself can begin the stressful event. How one reacts demonstrates specific the coping factors.

Further research into the psychology of coping strategies have created a plethora of coping and stress models. Using such models as a framework, or a conceptual base, has allowed researchers to further investigate the realities surrounding coping in chronic pain patients. Jensen, Turner, Romano, and Karoly (1991) explains:

Coping efforts or activities have been categorized along several dimensions. Lazarus and Coyne and Holroyd, for example, have partitioned coping strategies into two major types: those that are directed at solving or relieving the problem (problem-focused coping) and those that serve to manage the negative emotions associated with stress (emotion-focused coping). (p. 250)

Since coping is a response that either results in behaviorally or emotionally based reactions, or sometimes both, “the effectiveness of the coping strategy rests on its ability to reduce immediate distress, as well as to contribute to more long-term outcomes such as

psychological well-being or disease status” (Snyder & Dinoff, 1999, p. 5). The overall goal is diminishing the burden associated with chronic disease. Although pain is considered to be largely a sensory experience, there is a relationship between psychological factors (depression, helplessness, etc.) and coping strategies (Covic et al., 2000). To illustrate, take for example, rheumatoid arthritis suffers, an autoimmune disease that can often simultaneously occur with lupus and involves chronic pain.

According to Covic et al. (2000):

[arthritis patients] have higher rates of depression than the general population ... depression has been viewed as both a cause and an outcome of pain, while helplessness and a lack of control over events appear to mediate between the physical and psychological variables involved in the experience of RA. A belief that one has no control over the disease can lead to reduced efforts to cope with the disease, and consequently a poorer health outcome. (para. 2)

Some researchers also categorize coping efforts, in regards to chronic pain, into active and passive dimensions. It has been theorized that “passive coping is associated with greater pain, disability and depression, whereas active coping is associated with less pain, disability and depression” (Covic et al., 2000, para. 4). Brown et al. (1989), has defined the difference amongst the two dimensions as the following:

Active coping refers to the use of adaptive strategies in which individuals attempt to control their pain or to function in spite of their pain. In contrast, passive coping involves those strategies by which individuals relinquish the control of their pain to others or allow other areas of their lives to be adversely affected by their pain. (p. 653)

The central distinction between active and passive coping strategies is whether the patient is relying upon internal or external resources to control his/her pain. “Nicholas et al. (1992) expanded these definitions by specifying that active strategies involve an attempt by the patient to deal with the pain by using his/her resources, and passive strategies are characterized by helplessness and/or reliance on others” (Turek et al., 1995, p. 455).

Research into the field of coping, in regards to active and passive dimensions, is vital because numerous research studies have linked active coping strategies with positive adaptive behaviors, measures, and positive mental health. In regards to lupus patients specifically, the notion of healthy, positive coping abilities is further consequential because according to physicians, “All people with lupus experiences pain. The immune complexes that form in lupus cause carrying degrees of pain and discomfort” (Lahita & Phillips, 2014, p.183). And pain, more specifically chronic pain, has been found to result in higher levels of depression and mood and mental changes. As noted by physicians specializing in rheumatology (the field in which doctors specialize in to treat autoimmune and rheumatic diseases such as lupus), Dr. Robert Lahita and Dr. Robert Philips (2014):

There are four traditional categories of treatment for pain: chemical (the use of medication to destroy or block the chemical transmission of pain down the nerve fibers), surgical (cutting the nerves, the preventing transmission of the electrical impulse), physical (the use of physical therapy procedures such as exercise and hot/cold therapy to send different messages to the brain), and psychological (teaching one to deal more effectively with the pain by using coping strategies or by substituting some other feelings for the pain, the distracting attention from the

pain). In general, all four treatments work by interrupting the transmission of pain messages before the brain receives and interprets them. (p. 184-185)

It is also important to note that any type of stress, psychological and physical, can contribute to pain. “Stress causes a tensing of muscles, both increasing pain and making it more difficult to relax” (Lahita & Phillips, 2014, p.184). Fatigue, a primary symptom experienced by the majority of lupus sufferers, either due to the lack of sleep and/or because of the exhaustion linked to chronic illness, can also contribute to pain. “Fatigue does not allow tissues and joints to get the rest they need to repair themselves. This can contribute to the overall pain experienced (Lahita & Phillips, 2014, p. 184). Then, there is also the topic of depression. Depression can contribute to pain as well because “When patients are depressed, they tend to be less active, and thus they have more time to think about how they are feeling. Hence their awareness of their pain can be heightened” (Lahita & Phillips, 2014, p. 184).

The correlation established between active coping and positive mental health is especially important to patients of chronic illness because several studies have consistently reported a strong relationship between chronic pain sufferers and depression (Turek et al., 1995). However, individuals that employ an active coping style have been found to have less symptoms of depression. In contrast:

a style of responding to pain with relatively passive strategies (such as taking to bed, assuming the worst, restricting one’s activities, etc.) has been associated with, relatively poor adjustment (e.g. increased depressive symptoms, increased functional impairment, reduced life satisfaction). (Smith et al., 1997, p. 11)

Furthermore, recent studies have also shown that chronic pain can actually affect a person's brain chemistry and even change the wiring of the nervous system:

Cells in the spinal cord and brain of a person with chronic pain, especially in the section of the brain that processes emotion, deteriorate more quickly than normal, exacerbating many of the depression-like symptoms. It becomes physically more difficult for people with chronic pain to process multiple things at once and react to ongoing changes in their environment, limiting their ability to focus even more. [...] In addition to making some symptoms more profound, the change in brain chemistry can, create new ones, as well. The most pronounced of these are anxiety and depression. After enough recurring pain, the brain rewires itself to anticipate future bouts, which makes patients constantly wary and causes significant anxiety related to pain. Because chronic pain often mimics depression by altering how a person's brain reacts to discomfort and pain, chronic pain often biologically creates a feeling of hopelessness and makes it more difficult to process future pain in a healthy way. In fact, roughly one third of patients with chronic pain develop depression at some point during their lifetime (National Association of Injured and Disabled Workers, 2016, para. 4).

Although pain is physiological, and experienced at a multitude of levels and contexts, the perception of it can be exacerbated by "psychological interpretation;" (Lahita & Phillips, 2014, p. 185). Thus, techniques involved in pain control and management can reduce the perception of pain and therefore the discomfort caused by it. It is believed by many physicians that "it is helpful in guiding patients to learn methods of coping with their illness and to gain a sense of control by using preventative or

improvement strategies” (Lahita & Phillips, 2014, p. 202). Many researchers suggest cognitive, reframing methods in order to find the “positive” within the potential devastating diagnosis. This “benefit-finding” has been proven to be closely linked to better adjustment, coping abilities, and can lead to emotional benefit has a long tradition (Higgins & Leibowitz, 2001). To illustrate, Higgins and Leibowitz (2001) cite several examples:

when asked if their disability had brought purpose or meaning to their lives, for example, 64 percent of one sample of persons with spinal cord injuries answered affirmatively. *Benefit finding* has been found to aid in coping with myocardial, rheumatoid arthritis. (p. 35)

Benefits mentioned include, (a) realizing what is most important in life; (b) improved relationships with loved ones; (c) renewed spirituality; and (d) new opportunities for self-exploration (Higgins & Leibowitz, 2001).

Locus of Control

Research into the various dimensions of coping will illustrate how chronic pain does not have to be synonymous with depression and disability. Many individuals function normally and productively despite the presence of chronic pain. Positive functioning can be attributed to having an internal locus of control, which is related to active coping. Pain-related beliefs examined by researchers, especially in conjunction with active and passive coping dimensions, have attributed patients’ general locus of control to successful, active coping.

According to research regarding locus of control, conducted by Jensen et al. (1991):

The belief that outcomes are under the control of one's own behavior is described as reflecting an internal locus of control, whereas the belief that important outcomes are controlled by factors such as chance, luck or other people is said to reflect an external locus of control. (1991, p. 251)

Chronic pain patients who exhibit an internal locus of control orientation, as opposed to those with an external locus, have been hypothesized to be more likely to use active coping strategies and less likely to be depressed (Jensen et al., 1991). To further explicate this theory, Crisson and Keefe (1988) surmise that patients engaging in active coping strategies, whom are also exhibiting an internal locus of control, will be able to minimize, tolerate, and reduce their levels of pain.

Snyder and Dinoff (1999) assert that most instances of coping are conscious responses and are not reactions that are unconsciously based. Individuals are aware of their coping processes. Hence, the idea of locus of control comes into the forefront for chronic illness sufferers.

Lazzrus' defines coping within a stress and coping model that asserts coping as "constantly changing cognitive, behavioral, [and emotional] efforts to manage particular external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (as cited in Snyder, 1999, p. 9). In this case, coping is seen as a process based reaction, instead of trait based, which means that coping is a process that can be developed within anyone. Chronic illness sufferers have a better chance at handling disease activity and health management through this model.

It is posited by Frank (1999) that, "a fulfilling life is a tale about coping that works well" (p. v). A significant thought process when utilized by an individual with a

lifelong battle with varying highs and lows. It has been stated by many philosophers, world and religious leaders, and everyday people that the only certainty in life is the uncertainty of life. However, for chronically ill people, they are not only dealing with the “universal aspects of the uncertain human condition, but dealing with in an exaggerated form [of uncertainty] and with severely limited options” (Wiener & Dodd, 2001). Thusly, practicing locus of control directly effects a patient’s capabilities and quality of life.

Patient as Leader

The combination of utilizing active coping strategies and an internal locus of control can lead some patients to take charge of their own healthcare management and act as leaders. Studies have shown that patients who engage within the active dimensions of coping and healthcare management see outcomes dictated by their own behaviors (Jensen et al., 1991). With this mindset, patients are perceived as innovators and entrepreneurs of their own health management.

It has been surmised that “changes in health, in particular illness, such as chronic disease associated with the aging process, can give adults opportunities for learning and self-leadership” (Swann, 2014, p. 15). Individuals go from an inactive role, in which their course of treatment, resources used, and relationship between one’s self and the treating physician were determined by another individual (i.e., their current physician or insurance), to an active role. This active role empowers the individual to not only create a dynamic relationship between themselves and the treating physician, but it also enables the patient to experience feelings of control.

Due to the new role of patient-leader, an inescapable, devastating diagnosis creates a situation in which the patient may rise to the challenge. When in this position of

power and transformation, creating and viewing the patient as a leader, enables a sufferer of chronic pain and illness to transform an otherwise debilitating experience from a life-crisis to an opportunity. According to The Centre for Patient Leadership (CPL) (2012), this is an opportunity for patients to re-think their lives, reframe, and build new identities.

The notion of patients as leaders is relatively new. With individuals currently facing so many barriers to health, patient leaders have a valuable role to play in tackling the problems facing health and social care at a national and local level. According to patient leader advocate, David Gilbet, “amidst the chaos of reform and unprecedented challenges to improving health, the biggest asset we have - people who live with health problems and use services - remains untapped. Instead, patients are a problem to be solved, not the solution” (2012). Conferring with the current research, additional investigation into the theory of patient leaders is crucial to the development of better healthcare principles and understanding.

By investigating the role of the “active patient” within the context of the complex, varying nature of health management, further resources and valuable information can be explicated. As patients are expected to become more autonomous in connection with their healthcare management, healthcare and wellness materials are becoming easier to access, and:

[this is] an important step in preventing disease and in improving health care and patient satisfaction” (Papen, 2012, p. 105). ... The Department of Health supports the idea of the informed patient for the purposes of fostering a participating ‘partnership’ with health care providers (Papen, 2012). This view allows adults to self-lead; to choose how, when, where, and with whom they choose to receive

health services, in essence allowing adults to be involved in health care management decisions, participatory decision-making. (Swann, 2014, p. 15)

Further, it is hypothesized that the individuals who becomes empowered by being a patient leader can serve as inspiration and a model for persons recently diagnosed with a chronic illness. These individuals can then transform and utilize their positive coping skill set to inspire other chronic disease sufferers to take charge of their own health management as well. This theory is illustrated through the success of community education programs, seminars on chronic disease management, and the prevalence of support groups offered within many communities by privately and non-privately funded organizations.

Self-Directed Learning

Self-directed learning (SDL) is a crucial and well known, foundational field within adult education. Adult education encompasses many tenets that allow individuals to cope with life changes, especially variations in health, including increases in medical conditions and symptoms experienced by persons inflicted with chronic disease. Further, SDL is composed of a plethora of principles that is important and fundamental to the theory of adult learning, especially education as a transformative experience, which directly corresponds to the developing theory of patient as a leader.

SDL is a process in which a learner takes the initiative and responsibility to plan, implement, and evaluate his/her own learning experiences. It is grounded in the humanist philosophy because SDL asserts that there is unlimited potential for human growth (Merriam, Caffarella, & Baumgartner, 2007). This notion is vital. Not only to the overall theory of self-directed learning, but it is also foundational to patients learning to cope and

manage his/her illness; which is a lifetime commitment in most cases. Based on that premise, self-directed learning, in conjunction with lifelong learning, can aid an individual patient as much as any physical, medical, and holistic treatments. In fact, “self-directed learning is a central theme in disease management as a part of healthy aging” (Swann, 2014, p. 4).

The process of self-directed learning has been occurring unnoticed for centuries. Prior to the foundation of adult learning as a field of study, SDL has mostly gone unrecognized and lacked a formal name. Actually, self-directed learning mostly takes place without one even recognizing it as such because it is so imbedded in the everyday lives of individuals.

Self-directed learning can take place in any context, within a very broad spectrum of situations and environments, and it does not have to take place within a formal learning setting. In fact, self-directed learning can range from “how to” columns, self-help books, and pamphlets, to formal learning situations. According to Merriam et al. (2007), in most cases, people learn every day, it is usually self-directed in nature, and it most frequently happens outside of a classroom. Therefore, self-directed learning opens up the sphere of education to other criteria that are not usually espoused upon or expected.

This type of learning situation allows the needs of the learner to be the primary influence. In taking this notion into consideration, self-directed learning becomes crucial to health education and the development of the patient leader. Since the learner’s needs and contexts are the first things to be considered, and they are decided upon by that patient herself, then the need for the development of self-directed learning readiness is

clear. In fact, the most common aspect amongst the many theories of self-directed learning is that learner responsibility and initiative is key to successful educational pursuits. There are several types of models and theories regarding the development and implementation of self-directed learning. Each theory supports and offers different aspects of learning and human growth. However, what each of the theories agree on is that learner responsibility and initiative is key to the development of SDL.

Cyrill Houle developed the foundation for self-directed learning in 1961. He became interested in the motivations of learning, which sparked his interest into self-directed learning as a theory. Through this, Houle discovered that there are three types of learners. Houle's findings created the groundwork in which self-directed learning was established from. In particular, the discovery of the "learner-oriented" individual, people learning for the sake of learning, was one of his three findings. This was the foundation in which SDL has been built on. Houle had two advisees that took his theory of self-directed learning further, Allen Tough and Malcolm Knowles.

In 1971, a decade later, Tough created the first comprehensive study regarding self-directed learning, and he termed this "self-planned learning." He made several important discoveries. Tough believed that learning does not take place in isolation, that learning is a social construct. Furthermore, Tough also explicated that learners wanted to assume considerable responsibility and initiative for planning and directing their own learning activities. He also theorized that learners were specifically concerned with deciding on what to learn. All of which are important principles that support the connection between self-directed learning, education, and the development of the active patient.

In 1975, Knowles created the most widely used and accepted definition of self-directed learning. Knowles stated that with or without the help from others, self-directed learners diagnose their own learning needs, create learning goals, find resources, implement their own learning strategies, and evaluate their own learning experiences. Knowles based his conception of self-directed learning on his framework of andragogy (student-oriented learning). He believed that self-directed learning should be facilitated within the classroom and that the instructors should take part in the learning experience as well.

Furthermore, Knowles believed that as adults mature they will become more self-directed in their learning. There are three goals of self-directed learning: enhance the ability of adult learners to be more self-directed, to foster transformational learning as a fundamental aspect of SDL, and to promote emancipatory learning and social action as central to SDL (Merriam et al., 2007). Further, Caffarella proposed that the goals of self-directed learning vary, depending on the philosophical orientation of the researcher. She stated, “those [researchers] grounded in a humanistic philosophy posit that self-directed learning should have as its goal the development of the learner's capacity to be self-directed” (Caffarella, 2011, p. 9). Knowles and Tough wrote from this perspective as do Brockett and Hiemstra.

The investigation into self-directed learning goes beyond the goals and processes of learners themselves. Developed over the years, are many interactive and linear models focusing on self-directed learning. However, for the purposes of this current research study, the investigation into the characteristics and traits of self-directed learners are more important and imperative to this discussion. The literature can then move beyond

these notions and can be further categorized according to specific self-directed learning characteristics. Many investigations have taken place to uncover the connection between an individual's specific characteristics and his/her self-directed learning readiness and capabilities. Further research has also been conducted to further investigate any associations with self-directedness and personal variables regarding learning styles, level of education, etc. In fact, "two scales of self-directedness, one measuring readiness (Guglielmino, 1997), and one measuring personal characteristics (Oddi, 1986), have been used in a number of studies" (Caffarella, 2011, p. 10).

In the late 1970's, Lucy Guglielmino, under self-directed learning scholar, Huey Long, began investigating what characteristics, behaviors, and values created the make-up of a self-directed learner. Guglielmino developed a new methodology, a quantitative measurement scale called the *Self-Directed Learning Readiness Scale (SDLRS)*. Guglielmino also espoused upon ten traits of self-directed learning, including: initiative, independence, goal oriented, high degrees of curiosity, the ability to see problems as challenges, the ability to work independently, persistence, acceptance in responsibility for one's own learning, self-discipline, and enjoyment of learning. Furthermore, Guglielmino (1977) created a highly used operational definition that encompasses the self-directed learner: self-directed learning is a complex set of attitudes, values, and abilities that create the likelihood of an individual as being capable of SDL.

As learning in adulthood and maturation becomes more self-directed orientated and autonomous, self-directed learning is becoming a central focus in research. The ability to be self-directed is imperative to being a lifelong learner. Self-directed learning is a transformative experience that can bring learners to new heights, such as health

management. This is especially important considering how life altering chronic illness can be. When looking at health and wellness management, experts indicate certain characteristics such as, self-efficacy, motivation (Schechter & Lynch, 2010), and even empowerment amongst the features needed to actively and positively manage one's own healthcare. Those characteristics previously mentioned are also amongst the characteristics found to be related to self-directed learning.

It has already been established in this body of literature that learning is central to health, health decisions, and self-care, and thus adult educators' insights regarding lifelong, self-directed learning are critical in helping adults learn about their disease and make informed decisions. Researchers within the field has established self-directed learning to occur in a wide variety of contexts, and that more importantly, it can be a response to a personal need and conducted independently or collaboratively (Guglielmino, 2008). Thus, the effects of self-directed learning cannot be overlooked when considering health management. Changes in health, diagnosis of a disease, or the desire for improved health may trigger a need for learning. Adults will turn to healthcare providers, friends, family, support groups, the internet, and written material seeking out knowledge when faced with a new challenge regarding their healthcare and wellness. Through the use of these resources, and an investigation performed into the materials found by the patient, the individual can potentially experience a life changing, transformative learning experience that can positively affect his/her healthcare self-management.

Researcher and specialist, Janet Valente, asserts that:

Older adults need to understand the importance of the primary factors that contribute to health maintenance. It has been noted that those adults who have taken control of their health care are typically self-directing their own learning. (2011, para. 4).

A recent qualitative study performed by Valente (2011) illustrates several key factors and themes related to understanding how self-directed learning affects older adults aged 65-89 who practice self-directed learning as their primary approach to managing their own health. Six key factors, including “motivators to take control of health, health care behaviors, contextual factors, a learning cycle of self-directed health care, individual perceptions, and management of physical and environmental” (Valente, 2011, para. 22), were found to be relevant to understanding how older adults’ self-directed learning affects their health care.

Valente proposes that caregivers that are shown these findings can “increase their knowledge and understanding of the benefits of SDL” (2011, para. 1). She goes on to state that, “an obvious step is that many caregivers incorporate SDL into their own lives” (Valenta, 2011, para. 11). Valente suggests that if caregivers become self-directed learners themselves in order to, “effectively manage their own life tasks and their health care,” (para. 1) this could result in improved healthcare outcomes. In this particular case, the term “caregivers” extend beyond the traditional sense in that caregivers are considered not only the individuals whom are providing an ill person with care, but to also include the care provided by one’s self, due to the notions of the patient advocate and patient leader.

The Rise of Chronic Disease

According to the United States Centers for Disease Control and Prevention (CDC), currently, chronic diseases are the leading causes of death and disability in America (2016). Among those chronic diseases and conditions, such as heart disease, stroke, cancer, diabetes, obesity, and arthritis are among the most common, costly, and preventable of all health problems facing the world today (Center for Disease Control and Prevention [CDC], 2016). Chronic disease is defined as a human health condition or disease that is persistent or otherwise long lasting in effects. “Generally [chronic disease] cannot be prevented by vaccines or cured by medication, nor do they just disappear,” (Medicine.net, n.d., para. 1) it is a disease that last three months or more and cannot be, or very rarely are, cured. Chronic illnesses are dissimilar from a systematic illness due to its repeated and varying nature; “a chronic course is further distinguished from a recurrent course; recurrent diseases relapse repeatedly, with periods of remission in between” (Medicine.net, n.d., para. 1). According to the Australian Government’s Department of Health (2012):

Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability. Features common to most chronic diseases include:

- complex causality, with multiple factors leading to their onset
- a long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications

- associated functional impairment or disability.

The vast amount of manifestations of chronic diseases is reaching a global crisis. Data from the World Health Organization show that chronic disease is also the major cause of premature death around the world; even in places where infectious disease are rampant (Hiesler, 2006). Environmental factors, the aging population, exposure of disease diagnosis and new findings, genetic connections, and more global awareness has magnified the occurrence of chronic illness. The rise of chronic disease is reaching striking new heights. In fact, in 2002, 60 % of the 56 million deaths worldwide were somehow related to chronic disease (CSIS, 2013). Chronic disease accounts for 70 % of all deaths in the United States alone, which is 1.7 million deaths each year (CSIS, 2013). Further, “seven of the top 10 causes of death in 2010 [in the United States] were [related to] chronic diseases. Two of these chronic diseases—heart disease and cancer—together accounted for nearly 48% of all deaths” (CDC, 2016, para. 4). Although lupus, currently, does not impact those numbers of individuals, there are several factors that need to be considered. First, it is the symptoms of lupus that are generally treated within severe medical and ambulatory situations. Second, the disease may be misdiagnosed in many cases. Thus causing the inaccurate representation in numbers of deaths.

Further, due to new medical advances and the aging population (Baby Boomers, especially), the number of adults reporting a disability will most likely only increase (Hootman, Brault, Helmick, Theis, & Armour, 2009). The projected/expected increasing numbers have dire implications. Not only because they continue to rise, and are only expected to escalate, but also because as already described by the Centers for Disease

Control and Prevention, chronic disease is the leading cause of death and disability already in the United States.

This does not only have negative physical and social impacts, but the economic impacts of the rise in chronic illness can be devastating as well. In fact, treating people with chronic diseases accounts for 86 % of the nation's total health care costs (CDC, 2016). According to the Centers for Disease Control and Prevention (2016) there are high personal and societal costs to pay when it comes to chronic disease and their resulting impacts:

The Cost of Chronic Diseases and Health Risk Behaviors:

- In the United States, chronic diseases and conditions and the health risk behaviors that cause them account for most health care costs.
- Eighty-six percent of all health care spending in 2010 was for people with one or more chronic medical conditions.
- The total costs of heart disease and stroke in 2010 were estimated to be \$315.4 billion. Of this amount, \$193.4 billion was for direct medical costs, not including costs of nursing home care.
- Cancer care cost \$157 billion in 2010.
- The total estimated cost of diagnosed diabetes in 2012 was \$245 billion, including \$176 billion in direct medical costs and \$69 billion in decreased productivity.
 - Decreased productivity includes costs associated with people being absent from work, being less productive while at work, or not being able to work at all because of diabetes.

- The total cost of arthritis and related conditions were about \$128 billion in 2003. Of this amount, nearly \$81 billion was for direct medical costs and \$47 billion was for indirect costs associated with lost earnings.
- Medical costs linked to obesity were estimated to be \$147 billion in 2008. Annual medical costs for people who are obese were \$1,429 higher than people of normal weight in 2006.
- For the years 2009-2012, economic cost due to smoking has estimated to be more than \$289 billion a year. This cost included at least \$133 billion in direct medical care for adults and more than \$156 billion for lost productivity from premature death, estimated from 2005 through 2009.
- The economic costs of drinking too much alcohol were estimated to be \$223.5 billion, or \$1.90 a drink, in 2006. Most of these costs were due to binge drinking and resulted from losses in workplace productivity, health care expenses, and crimes related to excessive drinking.

Additionally, not only are the rates of chronic disease diagnosis skyrocketing, but the amount of chronic diseases developed in a single patient are on the rise as well. Studies show, “from 2001 through 2010, the prevalence of persons with multiple (≥ 2) chronic conditions (MCC) in the United States increased; approximately 26% of US adults had MCC in 2010, when 10 different conditions (i.e., hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, weak or failing kidneys, asthma, and COPD) were considered” (Ward, Schiller, & Goodman, 2012, p. 1).

Presently, it is common for patients to develop more than one chronic illness. In fact:

one of the most pressing challenges facing our health care system today is how to care effectively for the significant and growing number of Americans coping with more than one chronic condition. The population affected is significant: more than one in four Americans lives with multiple chronic conditions, including one in 15 children. (Partnership to Fight Chronic Disease, 2013, p. 1; Ward et al., 2012).

This is further complicated and problematic when considering that chronic illnesses are the leading cause of disability. “Driven by the aging of the U.S. population and growth in obesity and other risk factors, the prevalence of chronic disease is growing. More than half the nation's population is expected to have at least one chronic condition by 2020” (Partnership to Fight Chronic Disease, 2013, p. 6).

By the year of 2030, the number of U.S. adults’ aged-65-years and older, “will approximately double from current numbers to about 71 million” (Morbidity and Mortality Weekly Report, 2009, p. 421) individuals that will be affected by chronic disease. “The implications of this growing number of older adults include unprecedented demands on public health and senior services and the nation's health-care system” (Morbidity and Mortality Weekly Report, 2009, p. 421). However high the statistics, and the expectation of a further increase in diagnosis are, there is still a “notable” lack of research being conducted (Partnership to Fight Chronic Disease, 2013).

Moreover, even more shocking, the research conducted by Ward et al. (2012), regarding the number of civilian, noninstitutionalized U.S. adults with a single or multiple chronic illness suggests that the projections are believed to be a grossly underestimated number:

The NHIS [the 2012 National Health Interview Survey] estimates of the percentage of adults with one or more of the chronic conditions identified in the HHS [the US Department of Health and Human Services] standardized definition are likely conservative; the NHIS captures only 10 of the 20 chronic conditions included in the list of chronic conditions standardized to promote more consistent measurement, and this list of 20 conditions is itself a subset of the entire universe of chronic conditions. Mental health conditions included in the list of 20 conditions were not included in the NHIS Core questionnaires and therefore were not included in our study. This is especially problematic when examining younger adults. Finally, it should also be noted that the NHIS samples are from the noninstitutionalized civilian population and therefore do not include persons in long-term care or other congregant settings among whom the prevalence of MCC may be higher. (Ward et al., 2012, p. 2)

Therefore, the numbers that are already shockingly high do not depict the true voluptuous nature of the current and ever-increasing chronic disease epidemic.

Of the many chronic diseases mentioned by the Centers for Disease Control and Prevention (2015) is arthritis. Arthritis and other related diseases such as lupus, have one of the largest impacts on chronic illness and disabilities related to such, lupus for example. In “2005, the prevalence of self-reported disabilities among civilian, noninstitutionalized U.S. adults aged ≥ 18 years was 21.8%, and the total estimated population reporting a disability was 47.5 million” (Morbidity and Mortality Weekly Report, 2009, p. 421). Of the 47.5 million individuals reporting a disability, “Arthritis or rheumatism was the most common cause of disability overall (19.0%; estimated

population affected = 8.6 million) and for women (24.3%)” (Centers for Disease Control and Prevention, 2016; Morbidity and Mortality Weekly Report, 2009, p. 421). The fact that arthritis, and rheumatism in particular, is the leading cause of disability in America is especially pertinent to this overview of literature because it directly corresponds with the chronic illness under investigation here: lupus.

Rheumatism is an umbrella term for any disease marked by inflammation and pain in the joints, muscles, or fibrous tissue, especially rheumatoid arthritis and other autoimmune diseases. The term “rheumatism” has little meaning in today’s medical practices and dictionaries due to the varying nature of what it encompasses (MacGill, 2015). “While the word has long left many medical dictionaries, "rheumatism" is still used informally to describe symptoms” (MacGill, 2015, para. 4). The more generalized and chronic the syndrome, the more difficult it is to treat, “in non-medical lay language rheumatism and arthritis both tend to be used as vague, generic descriptions for an array of symptoms collected together to mean, among other things, joint pain and inflammation” (MacGill, 2015, para. 2). The term doesn’t designate any one specific illness; these conditions generally cause chronic and often intermittent pain affecting the joints and/or connective tissue.

According to the American College of Rheumatology (2015), there are more than 100 different rheumatic and arthritic conditions; including, but not limited to, osteoporosis, rheumatoid arthritis, gout, fibromyalgia, osteoarthritis, systemic lupus erythematosus, ankylosing spondylitis, and scleroderma. Although many of these disorders have very little in common in epidemiology they usually share similar

characteristics such as chronic pain, autoimmunity, involvement of multiple bodily systems, and are generally difficult to treat (American College of Rheumatology, 2015).

There are generally many misconceptions regarding syndromes of rheumatism; one of them being that these diseases are limited to older individuals. However, that is not the case; over 300,000 children live with arthritis and rheumatic related diseases in the United States alone (MacGill, 2015). Further, rheumatic diseases affect women two-to-three times more often than men, the disease is unlikely to go away, and effective management is paramount because there are generally no known cures (American College of Rheumatology, 2015; MacGill, 2015). Particular to the interest of this study is the chronic illness, lupus. A disease still referred to by many as rheumatism in lay terms of general description due to its chronic, autoimmune nature, and multiple system involvement.

Lupus Research

According to the United States National Library of Medicine, systemic lupus erythematosus (SLE) is “an autoimmune disease in which the body's immune system mistakenly attacks healthy tissue. It can affect the skin, joints, kidneys, brain, and other organs. The underlying cause of autoimmune diseases is not fully known” (2013, para.

2). When a person is suffering from lupus:

the body's immune system—its normal defense against harmful invaders including viruses and bacteria—turns its attack against the body's own organs, tissues, and cells. In some autoimmune diseases, the target of the attack is limited to a particular part of the body—the blood vessels, moisture-producing glands of the eyes and mouth, or insulin-producing cells of the pancreas, for example. In

lupus, the attack is systemic, meaning it affects many organs and organ systems including the skin, joints, heart, lungs, kidneys, and brain. The results can be disabling or even deadly. (Action Plan for Lupus Research, 2015, p. 4)

The cause of lupus is unidentified, but new developments are showing that there might be a connection to genetic, environmental, and hormonal factors. Currently there are no cures; however, there are various treatment options available. According to the Centers for Disease Control and Prevention:

diagnosis can be very difficult. The gold standard is a rheumatologist's diagnosis. The American College of Rheumatology (ACR) uses a standard classification scheme requiring 4 of 11 criteria for a research definition, although this is recognized to miss early and mild cases. Even so, there is: underdiagnoses because the presenting symptoms and signs are often not specific and not recognized as SLE. (2015, para. 1)

Furthermore, the evolution of the disease is highly variable—disease activity ranges from minor complaints to death, and symptom manifestations often waxes and wanes over time. Patients can experience periods of time with little to no relative symptoms to significant times of disease activity.

Due to lupus' vast array of symptoms and complications it is a difficult disease to treat. Lupus is highly individualized. What might be common in one lupus patient can be completely unrelated to another. In fact:

The most heterogeneous of the autoimmune diseases, lupus is also one of the most difficult to understand and treat. Sixty years ago, about 50 percent of those with lupus died within five years of their diagnosis. Today, [...] 97 percent of lupus

patients are living five years after diagnosis, and 90 percent continue to survive after 10 years. The transformation of lupus from a disease with a high mortality rate to one that is chronic has led to an increased need for better therapies that can manage long-term symptoms. (Action Plan for Lupus Research, 2015, p. 4)

Despite the fact that lupus is a chronic disease, and a major cause of disability in the United States, there is still very little research on the illness. This situation is exacerbated by the recognition that “roughly sixteen thousand new cases are diagnosed each year” (Lahita & Phillips, 2014, p. 29).

The history of lupus is divided into three periods of time: classical, neoclassical, and modern. During the classical stages of lupus development the first account of the disease was described only pertaining to skin lesions:

the word lupus means wolf in Latin, as the destructive injuries the disease caused brought to mind the bites of this animal [...] after an extensive review of the works of the Medieval and Renaissance periods, concluded that any process involving ulceration or necrosis of the lower limbs or face was loosely labeled lupus before the mid-19th century. (Mallavarapu & Grimsley, 2007, p. 1)

It wasn't until 1948 that the diagnosis of lupus evolved past dermatological symptoms. This is when the modern period of lupus research and discovery took shape. “When Mayo Clinic hematologist, Malcolm Hargraves, discovered the LE cell. Serum from patients with lupus erythematosus was added to bone marrow preparations from normal subjects” (Mallavarapu & Grimsley, 2007, p. 1). This paved the way to illustrating the autoimmune process underlying lupus. Although, however great of a breakthrough this was for lupus research, it wasn't until 1958, a decade later, that a

laboratory test was developed as the principal diagnostic test for detecting the disease. This diagnostic test can also be used as a possible evaluation method to determine the severity of the current activity of the disease. Afterwards, it wasn't until "a committee of North American rheumatologists met in 1971 and published a clinical and analytical scheme for the diagnosis of this disease" (Mallavarapu & Grimsley, 2007, p. 1). Prior to this development lupus diagnosis was haphazard and unreliable. Even now, the disease is difficult to diagnosis and most patients go several years without receiving an official diagnosis, if ever.

Lupus Timeline. The evolution regarding the understanding and treatment of the disease, as documented in the literature, has been slow; and, this is due to the lack of research in the field of lupus studies.

- Lupus (Latin for 'wolf') acquired its name during the 13th century from physician Rogerius. It was so named because of the skin lesions (that are a prevalent symptom of the disease) was originally thought to represent the wounds that resulted from an attack by a wolf.
- A trademark butterfly rash appears on the malar parts of the face (above the cheeks), and it was also first mentioned in the 13th century and thought to be from the bite or scratches of a wolf.
- The actual term lupus erythematosus was first mentioned by Pierre Cazenave and it is the first detailed modern description of lupus. The lesions now referred to as discoid lupus were described by Cazenave under the term 'erythema centrifugum' (Lupus Research Institute, n.d.).

- The first published illustrations of lupus erythematosus in 1865 were included in Austrian dermatologist, Ferdinand von Hebra's text, *Atlas of Skin Diseases*.
- In 1872 Moriz Kaposi first described the systemic nature of the disorder. He proposed that there were two types of lupus erythematosus; the discoid form and a disseminated form.
- Niels Ryberg Finsen, in 1903, was awarded *The Nobel Prize* in Physiology or Medicine “in recognition of his contribution to the treatment of diseases, especially lupus vulgaris, with concentrated light radiation, whereby he has opened a new avenue for medical science” (Lupus Research Institute, n.d.).
- There was much confusion regarding the diagnosis of lupus until well into the 20th century. It was often confused for tuberculosis, disseminated gonorrhea, and many skin disorders.
- Only in the 1930s and 1940s did pathologists look at organs such as the kidneys and skin and realize the common changes in these organs had similarities in patients with lupus. Together these formed the typical aspects of lupus.
- Immunology was in its infancy in the 1930s and 1940s, and the classical description of antibody structure was not to take place for some decades. No one knew the mechanism through which lupus could, so globally, damage so many organs of the body. No one really understood this newly described illness, which counted rash, kidney failure, and sun sensitivity among its list of characteristics.
- In the 1940s came the association with the false-positive test for syphilis, the discovery of the LE cell, and the idea that these phenomena might have something to do with “blood proteins.” These proteins were later called antibodies, and it

was suggested that they might be reacting with normal tissues. All of these discoveries were important in the understanding and diagnosis of lupus (Lahita & Phillips, 2014).

- Coincidentally, the discovery of cortisone in 1938 by Philip Hench provided the first and greatest therapy for lupus.
- The 1950s brought the fluorescent antinuclear antibody assay, and important test in the diagnosis of lupus, and the discovery of autoantibodies such as Sm and PNP. These autoantibodies form the basis for our understanding of the disease process of lupus—how we diagnose it and how the disease affects the body. In addition, the 1950s brought about important insight into the genetics of the disease. All of this added significantly to knowledge about lupus (Lupus Research Institute, n.d.).
- Since the 1950s, much research has focused on the following areas: molecular genetics (in order to learn more about the immune response), hormones and their importance, and, more recently, the development of several new drugs. Although lupus research has come far in the past twenty-five years, it will take an understanding of the cause of the disease—currently unknown—in order to develop a targeted cure.
- 1969 the first lupus textbook, *Dubois' Lupus Erythematosus*, was published
- In the early 1980s a new condition called antiphospholipid syndrome was inexorably linked to lupus. It is troubling because it causes bleeding and clotting. It is usually a condition of “sticky blood” that can result in blood clots in the lungs

and brain. The addition of factors concerning the syndrome resulted in a revision of the criteria for the classification of lupus.

- In the first decade of the twenty-first century came a number of significant advances [...] These include the use of newer biological agents for lupus such as belimumab and rituximab. Newer drugs previously used for transplant organs came into use as well (Lahita & Phillips, 2014, p. *x-xii*; Lupus Research Institute, n.d.).

Only recently has interest in the disease become more prevalent. The past two decades of research have produced a vast array of new information and development in improving the understanding of lupus. Which is significant to note because of the vast amount of individuals suffering from this chronic illness. Even by the most conservative estimates, “there are at least 322,000 Americans with definite or probable lupus” (Action Plan for Lupus Research, 2015, p. 4). Further, “recent independent surveys have suggested a prevalence as high as 1.5 million” Americans are officially diagnosed (Action Plan for Lupus Research, 2015, p. 4). Currently, privately and publically funded organizations, such as the Lupus Foundation of America, Inc., the Lupus Research Institute, and Alliance for Lupus Research, have been the largest contributors to the creation and furthering of lupus research. Unfortunately, there has only been the creation of one lupus-specific drug produced solely for the treatment of lupus—belimumab (Lupus Foundation of America, 2013).

There are many unique characteristics of lupus. According to recent discoveries involving genetics, it is mostly believed that the “underlying reason for certain racial

prevalence probably depends on genetic makeup” (Lahita & Phillips, 2014, p. 26). Lupus occurs more often in specific ethnic groups:

The Caucasians incidence is roughly 1:1,000. In African Americans, the numbers are higher 1:250; in Latinos, the numbers are 1:500. The disease is quite common in some countries, such as China, Cambodia, and Thailand. Unfortunately there are no statistics as of yet for the incidence in Asian Americans, but it is likely to be a higher than that seen in the African American population. (Lahita & Phillips, 2014, p. 26)

It is further asserted by Lahita and Philips (2014) that it may seem that certain ethnic groups might experience the disease at a more severe level. To illustrate:

It appears that African American women have much more active lupus than other ethnic groups. In fact, the complications from severe kidney disease are greater in the African American community. The reasons for this difference in activity do not seem to depend on socioeconomic factors; however, the most severe manifestations are usually worse in people who wait to have their disease diagnosed or who have poor access to competent physicians. (Lahita & Phillips, 2014, p. 26-27).

“Health related quality of life may be worse in patients with SLE compared to other chronic diseases” (CDC, 2015, para. 8). Data has shown that as the duration of lupus-related disease activity and symptom manifestation increases, the percentage of individuals working decreases, “on average only 46 percent of persons with SLE reported being employed” (CDC, 2015, para. 8). Quality of life is further impacted due to the tendency for individuals who are diagnosed with lupus to suffer from other autoimmune

problems and syndromes in addition to this disease. This frequency to hoard diseases by the lupus patient means that they have to undergo additional various and differing treatments; most of which are strong immunosuppressive medications with dire side effects.

Patients also undergo many monetary costs and expenses that have personal affects as well as societal. Bernatsky et al. (2006) believe that lupus can monetarily exasperate disease sufferers. There are many costs associated with chronic illness, including prescriptions, multiple specialists, expensive diagnostics, higher insurance premiums, and etc. “No national cost estimates exist specifically for SLE. However, the average hospital charges for diffuse connective tissue disease, which includes SLE, was about \$13.3 billion US dollars in 2011” (Bernatsky et al., 2006, p. 2550).

Although there have been a definitive lack in research, due to the prevalence, unique characteristics, and renewed interest in the rise of chronic illness, the field of lupus studies is experiencing a surge of interest. Not only are the private, not-for-profit agencies already mentioned in the literature creating new developments, but the National Institute of Health is placing a high priority on cross-disciplinary research between government and private agencies as well. After a considerable amount of canvassing and grass-root efforts lead by organizations such as The Lupus Foundation of America, Inc. and The Lupus Research Institute, the National Institute of Health (NIH) released a new report, the *Action Plan for Lupus Research*, on January 13, 2016. The report, created by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), part of the NIH, is a follow-up requested update to a 2007 report titled, *The Future Directions of Lupus Research*. According to the Lupus Foundation of America:

The updated report reflects the current need and gap in lupus research for helping to improve upon a basic understanding of the disease and to identify targets for advancing lupus drug development. [...] *The Action Plan for Lupus Research*, as well as the recently released *National Public Health Agenda for Lupus*, will help guide the lupus community in its efforts to reduce the time to diagnosis, to develop programs and services that will benefit people with lupus, their caregivers and health care providers, and to develop new treatments and clinical trial models. (2016, para. 3)

The research plan identifies and examines opportunities to increase the scientific understanding of lupus. This will ultimately lead to safer and more effective treatments and, eventually, curative strategies. The research plan will help prioritize and increase progress for future lupus research.

Chapter Summary

The researcher framed the current available literature to create a knowledge base in which the research study was based upon. The chapter illustrated barriers to health management in order to highlight the monstrosity of the healthcare field and the many barriers that patients are presented with, which include health literacy, doctors' views of the patients', lack of proper communication, and the complicated nature of the health system in America. Furthermore, the role of the relationship between self-healthcare management and the learner was explored.

The importance of learning in conjunction with proper health management was also noted. Coping as a healthcare management strategy, and more specifically, the active and passive dimensions of coping, were discussed. The importance of active and passive coping orientations directly relates to the patient's general nature of his/her locus of control, which if internalized can create a patient leader. The notion of a patient leader was relatively new within the healthcare field. However, this lead directly into the role of self-directed learning, and its role and importance to proper healthcare management.

Next, the rise of chronic diseases was demonstrated, which is escalating at an alarming rate within North America. Moreover, the destructive nature of one such chronic disease, lupus, was introduced. However important it is to understand the devastating nature of this chronic illness and the pain associated with this disease, it is also just as important to explicate upon the lack of research executed on it. Especially considering the fact that at least 1.5 million Americans are currently living with lupus; with more than 16,000 new cases reported annually (Lupus Foundation of America, 2013). These statistics are not even as accurate as they could be. Due to the lack of

research, there have not been any large-scale studies that reflect the true number of individuals living with lupus in the U.S., and thus the numbers reported are not accurate (Lupus Foundation of America, 2013).

III. METHODOLOGY

The purpose of this study was 1) to examine the significance, if any, of a patient's active or passive role in terms of his/her health management; 2) to determine if a relationship existed between his/her active and passive scores and his/her self-directed learning readiness, and 3) to identify if his/her view of one's self as a patient (when diagnosed with a chronic disease) impacted his/her own personal health management. This research endeavor was a quantitative analysis of two specific instruments measuring a patient's self-directed learning readiness and his/her ability to manage and/or cope with the illness.

In particular, the patient's approaches to learning, more specifically self-directed learning and personal characteristics, were analyzed and compared to the characteristics associated with the elements of self-directed learning readiness through the use of an open-ended question. Furthermore, the researcher attempted to identify self-directed learning elements that were essential for patients who identified as actively coping with his/her chronic illness. These characteristics were acknowledged in hopes of further research and program implementations. This would develop leadership abilities and self-directed learning readiness characteristics in chronically ill patients in order for them to have a more positive outcome and successfully manage his/her own health by actively coping.

The study included 100 participants taking the *Vanderbilt Pain Management Inventory*, an 17-item, self-report measure that assessed how often chronic pain patients

use active or passive coping strategies when their pain reached a moderate or greater level of intensity. The active and passive patients (decided on by the *Vanderbilt Pain Management Inventory* tool) were then compared in levels of self-directed learning readiness by the *Self-Directed Learning Readiness Scale*. Of the 100 surveys, 81 participant's data was completed and used.

The researcher used statistical analysis to determine to what degree the active and passive groups contrasted each other. Next, self-directed learning readiness was measured in both the passive and active groups and the scores were compared in order to ascertain in what ways specific characteristics of self-directed learning attribute to actively coping with chronic illnesses. Furthermore, an optional open-ended question was asked of the patients regarding their perception of their coping capabilities and its effect on their self-health management in order to discern characteristics particular to an active patient.

Research Questions

1. What is the relationship, if any, between the *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients?
2. What is the relationship amongst the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score?

Research Hypotheses

1. There will be a statistically significant relationship in the scores of self-directed learning readiness if a patient is defined by the *Vanderbilt Pain Management Inventory* as being an active versus passive patient.

2. There will be a statistically significant relationship between the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score.
 - a. Age will significantly affect the relationship.
 - b. Education will significantly affect the relationship.
 - c. Ethnicity will significantly affect the relationship
 - d. Gender will significantly affect the relationship.

Sampling

Purposeful sampling was used in this study. The researcher accessed a unique population. Individuals, throughout the state of Florida, self-reported as being diagnosed with lupus, who participated in seminars and support groups provided by the Lupus Foundation of America, Inc. and the Lupus Foundation of Florida were selected. Medical professionals and practices were not utilized to access lupus patients. Due to patient privacy laws, sampling was limited to only persons whom openly expressed and self-identified their diagnosis participated in the study. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), was established to protect the security surrounding the sensitive nature of an individual's health information. Thus, the only way to access participants for this study was through the organizations listed and with persons who met the criteria.

Both formal and informal groups were visited to locate participants. The following list of sites suggest the variety of locations that were visited. Example of sites visited are provided in the table below (see Table 2. Data Collection: Dates and Locations). Data collection locations, dates, and times:

Table 2
Data Collection: Dates and Locations

Monday, March 9 th , 2015	St. Mary’s Hospital: Lupus Foundation of America West Palm Beach Support Group
Thursday, March 19 th , 2015	Bethesda Memorial Hospital: Lupus Foundation of America South Palm Beach Support Group
Saturday, March 21 st , 2015	Shands Hospital: Lupus Foundation of Florida Gainesville “Living Well With Lupus” Seminar
Saturday, March 21 st , 2015	Farmworkers Association of Florida: Lupus Foundation of Florida Apopka, FL. Support Group
Thursday, April 9 th , 2015	North Sarasota Library: Lupus Foundation of Florida Sarasota “Living Well With Lupus”
Saturday, April 11 th , 2015	Support Group: Lupus Foundation of Florida Spring Hill
Saturday, April 11 th , 2015	Mid Pinellas/Largo: Lupus Foundation of Florida Shiloh Missionary Baptist Church, Largo, FL. Support Group
Tuesday, April 14 th - 15 th	2015 Lupus Advocacy and Awareness Day in the Florida Legislature Lupus Foundation of America: Tallahassee, FL- Capital Hill
Saturday, April 18 th , 2015	Orlando Seminar- Lupus Foundation of Florida “Living Well With Lupus” at Leu Gardens
Saturday, May 2 nd	Walk to End Lupus Now: Lupus Foundation of America Florida Chapter: Palm Beach Zoo
Saturday, May 30 th	Annual Lupus Wellness Day: Lupus Foundation of Florida Dr. P. Phillips Hospital: Orlando, FL.
Saturday, May 30 th	“Ask The Experts” Lupus Seminar Series: Lupus Foundation of America Nova University: Orlando, FL.
Tuesday, June 2 nd	Central Fl. Support Group- Lupus Foundation of America Central Florida Regional Hospital: Sanford, FL.

Procedures

Quantitative Procedures: The researcher gained access to multiple lupus support group meetings and seminars to select participants for the study. All subjects in the study took the *Vanderbilt Pain Management Inventory (VPMI)* in order to determine which patients were in the active or passive group. Next, the participants were administered the *Self-Directed Learning Readiness Scale (SDLRS)*.

The active and passive patients (assessed by the *Vanderbilt Pain Management Inventory* tool) were compared in levels of self-directedness. The results were quantified; the active patients' results were compared to the passive patients' results. Statistical analysis software SPSS was used by the researcher to determine to what degree the active and passive groups contrasted each other. The scores were then compared in order to ascertain the relationship amongst the two groups. Further, the sample demographic characteristics, age, ethnicity, education level, and gender, which may have affected the relationship amongst a patient's self-directedness and coping abilities, was investigated.

Qualitative Procedures: Lastly, in order to ascertain in what ways specific characteristics of self-directed learning may have attributed to patients whom identified as actively coping was investigated. Through the use of an open-ended question, documentation of self-directed learning, in the context of one's own personal health management, was examined. In particular, the participants' approaches/perceptions to health management and personal characteristics were analyzed and compared to the characteristics associated with the elements of self-directed learning and active and passive coping. Through the question, "Do you believe that being actively involved in

your healthcare affects your health management? Please explain.” The researcher drew attention to self-directed learning in this manner.

The researcher used the data collected to identify characteristics of self-directed learning based on the work of Guglielmino (1977). The characteristics under investigation were based on the following summary of her work:

A highly self-directed learner, based on the survey results, is one who exhibits initiative, independence, and persistence in learning; one who accepts responsibility for his or her own learning and views problems as challenges, not obstacles; one who is capable of self-discipline and has a high degree of curiosity; one who has a strong desire to learn or change and is self-confident; one who is able to use basic study skills, organize his or her time and set an appropriate pace for learning, and to develop a plan for completing work; one who enjoys learning and has a tendency to be goal-oriented. (Guglielmino, 1977, p.73)

The priori code method, using codes developed before examining the data, was used in order for the data to be compared to characteristics of self-directed learning established by Guglielmino (1977). Even with this process in place, some of the codes were not covered by the characteristics of self-directed learning. No attempts were made to force fit the data to the codes.

The coded quotes were created by assigning units of meaning to words, phrases, sentences, or whole paragraphs (Johnson & Christensen, 2012, p. 520). Categories of themes were established and assigned various responses in the identified themed areas and quantified. After reviewing the categories and the related coded quotes some were added and some were dropped.

No attempts were made to identify the participants by name or other related characteristics. The participants' identities were kept anonymous from other participants and the researcher. No attempt was made by the researcher to determine if the information reported by the patients was accurate or inaccurate. As with any self-reporting of data, this was one limitation of the study. Based on the data available, the researcher examined the responses, reached a consensus of the predominant characteristics, and compared those characteristics to characteristics associated with self-directed learning.

Instrumentation

The instruments that were used within this study were the *Self-Directed Learning Readiness Scale* (Guglielmino, 1977) and the *Vanderbilt Pain Management Inventory* (Brown & Nicassio, 1987).

Self-Directed Learning Readiness Scale: "The SDLRS is recommended as having power to identify self-direction in learning behavior" (Long & Agyekum, 1983, p. 77). It is a method for evaluating an individual's perception of their skills and attitudes that are associated with self-directedness in learning. The scale is structured around eight factors, attitudinal and personality, which are linked to self-directedness. However, the total score, and not subscales, was used for the purposes of this study. The *SDLRS* is a 58-item, self-report assessment with Likert-type responses that assessed the attitudes, values, and abilities of learners relating to their readiness to engage in self-directed learning at the time of response (Guglielmino, 1977). The instrument yields a total score ranging from 58 to 290. The mean score for the *SDLRS* is 214 (see Appendix A).

The SDLRS is one of the most often cited and validated self-directed learning instrument's. Guglielmino (1977) determined content validity by using the Delphi process with 14 experts in the field of self-directed learning. Finestone (1984) further supported Guglielmino's validity through a review of literature on self-directed learning. Guglielmino and Murdick (1997) states:

The latest reliability estimate of the SDLRS, based on a split-half Pearson product moment correlation with Spearman-Brown correction is .91 [for the total score]. The sample consisted of 3,151 individuals from a wide variety of settings and throughout the United States and Canada. The majority of the validity studies of the SDLRS have focused on convergent validity; that is, they examine correlations of SDLRS scores with measures that would be expected to correlate positively, such as number of learning projects conducted, hours spent in self-planned study, or observer ratings or behaviors thought to be indicative of self-directed learning. (p. 12)

Vanderbilt Pain Management Inventory: The *Vanderbilt Pain Management Inventory* (Brown & Nicassio, 1987) was created to assess two forms of coping with chronic pain: active and passive. The *VPMI* is an 17-item, self-report measure that assesses how often chronic pain patients use active or passive coping strategies when their pain reached a moderate or greater level of intensity (see Appendix B).

Subjects rate the frequency with which they used specific coping strategies when their pain reached a moderate or greater level of intensity by circling the number on a four-point scale which best describes their pain management. The scale was developed in order to assess coping strategies used by individuals suffering from chronic illness. More

specifically, the *VPMI* was developed using a sample of rheumatoid arthritis patients (Brown & Nicassio, 1987), and it has been employed in a myriad of other studies consisting of chronic illnesses and pain ranging from fibromyalgia, various types of arthritis, and chronic neck and back pain sufferers.

The *VPMI* consists of two internal subscales: active and passive. “The scales of the *VPMI* appear to have adequate internal consistency and test- retest reliability (Brown & Nicassio 1987; Smith & Wallston, 1992)” (as cited in Turek et al., 1995, p. 457). “Reported internal consistency coefficients for the Active Coping scale have ranged from 0.71 to 0.73 and coefficients for the Passive Coping scale have ranged from 0.82 to 0.83 (Brown & Nicassio 1987; Smith & Wallston, 1992)” (as cited in Turek et al., 1995, p. 457). However, for the purposes of this study, one single score was used in order to differentiate between active and passive patients.

The first nine questions posed on the *VPMI* represent the Passive scale (composed of implications such as, “telling others that it hurts a lot,” “reducing your social activities,” and “depending more on others for help with everyday tasks”) and the remaining eight questions represent the Active scale (composed of statements such as, “trying to distract your attention away from pain,” “ridding the mind of upsetting thoughts,” and “doing physical exercise”). According to Brown and Nicassio (1987) the subscales are internally consistent and slightly negatively correlated. One single score is calculated. The mean score for the Active Coping scale was 20 (within the 7-35 score range) (Brown & Nicassio, 1987; Turek et al., 1995). The mean score for the Passive Coping scale was 31 (within the 11-55 score range) (Brown & Nicassio, 1987; Turek et

al., 1995). One total score was used for this study. Based upon the total score of each participant, it was specified what form of coping the individual was engaged with.

Data Collection Methods

Active versus passive patients was determined by the individual's score on the *Vanderbilt Pain Management Inventory*. Self-directed learning readiness was determined by the *Self-Directed Learning Readiness Scale*. The participants' perception regarding whether or not he/she was actively managing/coping was determined by a "yes" or "no" question. An optional, open-ended question, concerning the patient's role in managing/coping with his/her diagnosis, was also provided at the end of the survey. Data was analyzed using descriptive statistics, Pearson correlation, and multiple regression.

Data Analysis

This study explored the selected demographic, active and passive coping abilities, and characteristics associated with self-directed learning readiness. Data were analyzed using the computer software package, IBS SPSS version 21. An alpha level of .05 was used to assess statistical significance. Microsoft Excel and Word 2013 was used to organize, compile, and quantify the open-ended question results.

Scoring Method

In order to properly address this research investigation all data were analyzed by using the statistical software SPSS. In order to properly address this investigation, the researcher established demographics and the level of a lupus patients' self-directed learning readiness, as well as established the level of a lupus patients' active or passive coping abilities. Measures of central tendency (Mean, Median, & Mode), variability

(Standard Deviation, Variance, and Range), and percentages was used for comparative purposes by the researcher.

The researcher utilized an array of descriptive statistical techniques to analyze and interpret the data achieved in question one and two.

Chapter Summary

This chapter presented the methodology of the research study *Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness*. A step-by-step methodological plan was illustrated by restating the purpose of the study, research questions, and hypothesis that guided the investigation. Furthermore, the researcher provided the procedures that were taken, sampling plan, and the instruments used, as well as the data analysis and scoring method. Data collection location and times were also provided.

IV. RESULTS

The purpose of this study was 1) to examine the significance, if any, of a patient's active or passive role in terms of his/her health management; 2) to determine if a relationship exists between his/her active and passive scores and his/her self-directed learning readiness, and 3) to identify if his/her view of one's self as a patient (when diagnosed with a chronic disease) impacted his/her own personal health management.

Research Questions

Two research questions guided this research study:

1. What is the relationship, if any, between the *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients?
2. What is the relationship amongst the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score?

Descriptive Information

For this study, the sample of 81 (n= 81) individuals, positively diagnosed with lupus, were selected for analysis. This sample of 81 participants, out of the 100 surveys received, were correctly completed included: (a) *The Self-Directed Learning Readiness Scale*; (b) *The Vanderbilt Pain Management Inventory*; (c) the open-ended question

regarding their perception of their health management status; and (d) met the criteria of having a positive, physician diagnosis of lupus.

Descriptive Statistics

The total number of participants (n = 81) represented diverse demographics (see Table 3. Demographic Characteristics). However, there were a disproportionate amount of individuals' identifying as Caucasian, despite there being a higher incidence of African-Americans being diagnosed with lupus. Ethnicity (see Figure 3. Ethnicity) percentages were as listed: 48 (59.26%) Caucasian; 18 (22.22%) African-American; 13 (16.05%) Hispanic; and 2 (2.47%) Native American (see Figure 3). Of the 81 participants, 76 (93.83%) were identified as female and 5 (6.17%) were identified as male (See Figure 4. Gender).

The dominant level of education attainment was identified amongst the participants as Bachelor's degree at 23 (28.40%); the rest of the education percentages are listed: 1 (1.23%) below secondary level; 13 (16.05%) received a high school diploma; 15 (18.52%) completed some college; 10 (12.35%) received an Associate's degree; 23 (28.40%) received a Bachelor's degree; 14 (17.28%) received a Master's degree; 4 (4.94%) earned a PhD; and 1 (1.23%) completed some post graduate work (see Table 2). The ages ranged from 22-years to 76-years, with the average age identified as 50.14-years-old. Demographic data are listed in Table 3 and ethnicity and gender are illustrated by Figure 2 and Figure 3.

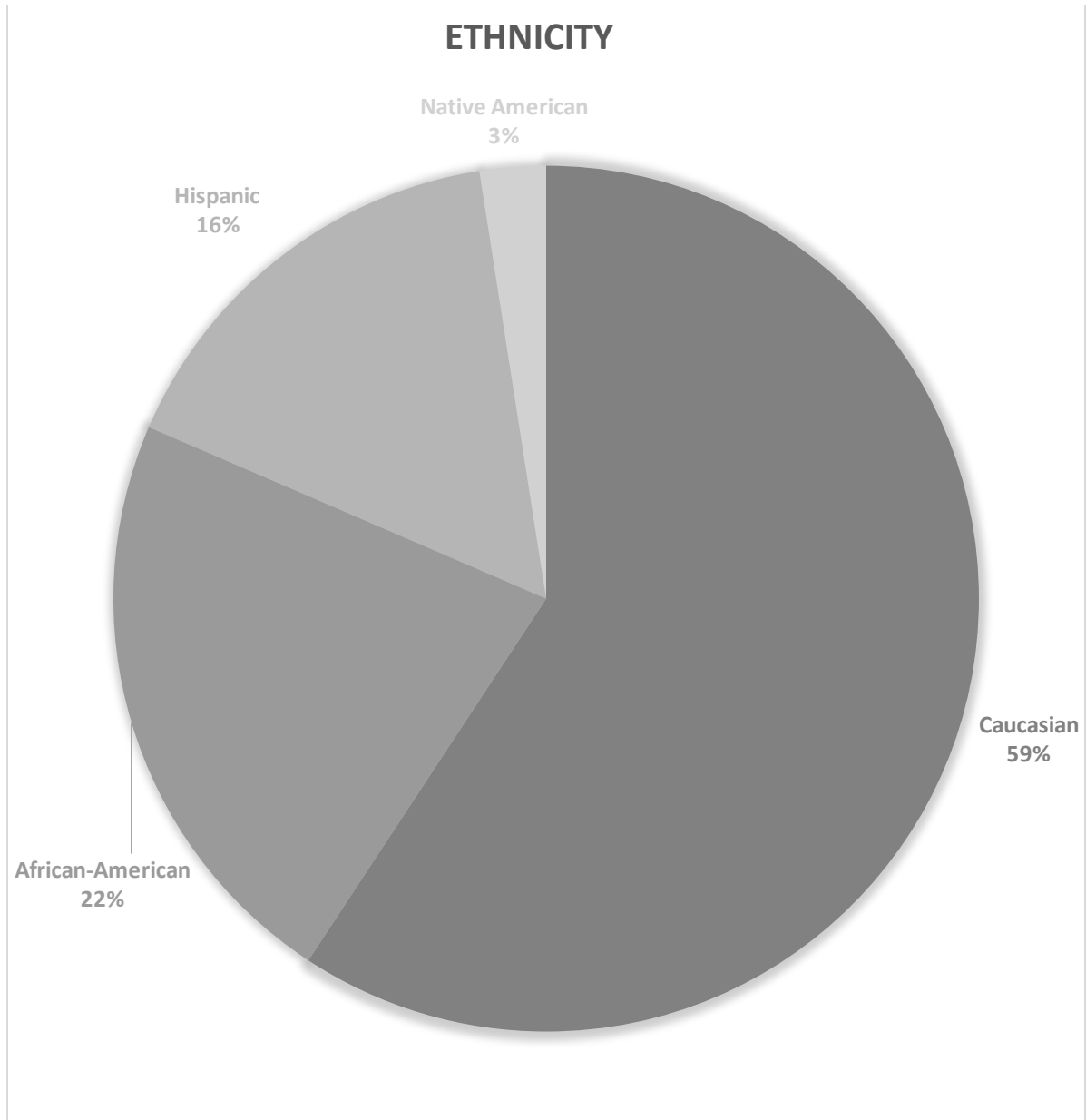


Figure 2. The ethnicity composition of study participants.

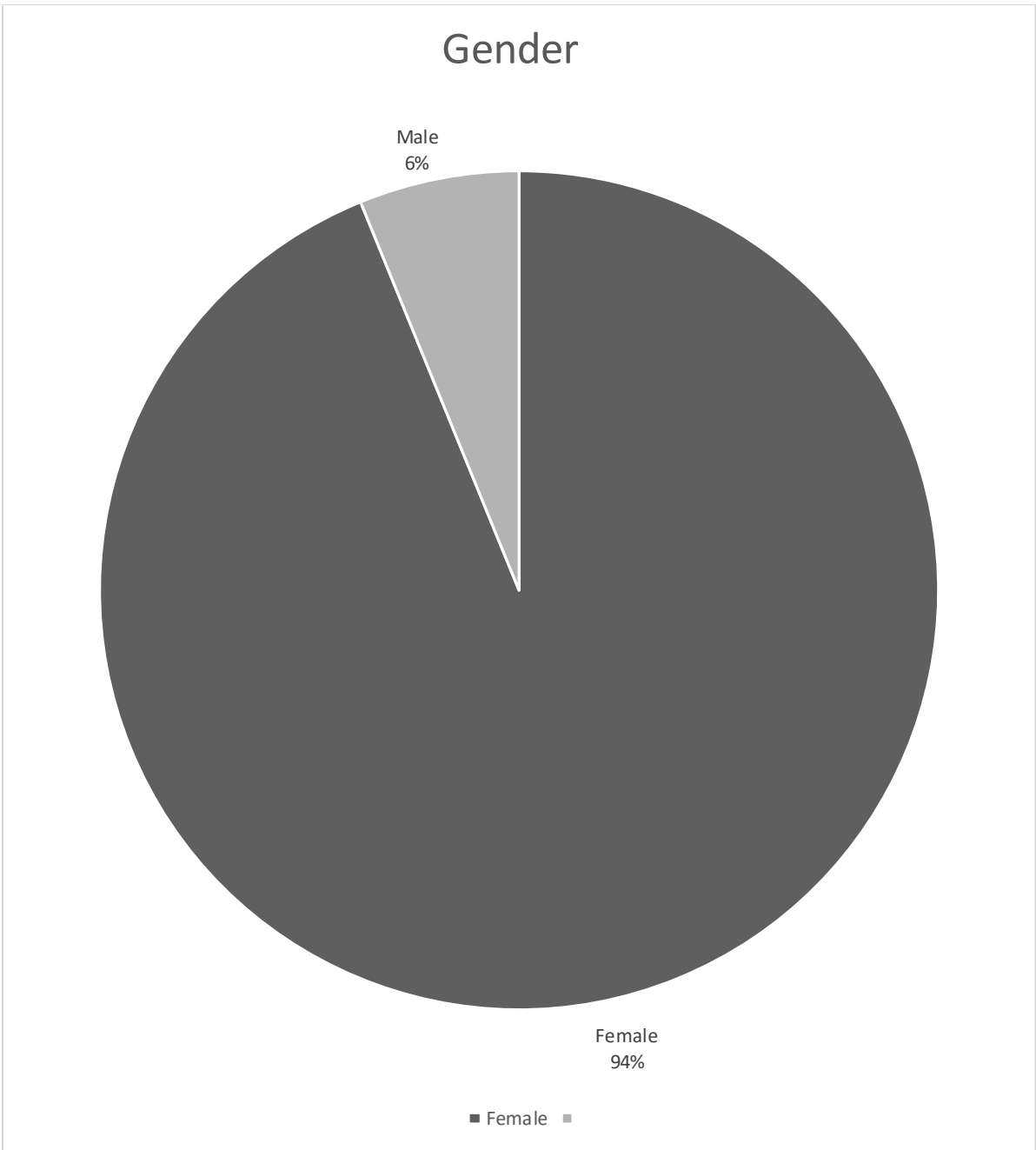


Figure 3. The gender composition of study participants.

The mean score determined by the *Self-Directed Learning Readiness Scale* was 229.49, with ranges from 148.00 to 281.00. The scores placed the individuals in this study at an “above average” level of readiness for self-directed learning (Guglielmino, 1977).

The mean score determined by the *Vanderbilt Pain Management Inventory* was 46.79, with ranges from 29 to 61. Thus, placing the individuals in this study within the “active patient” range. When asked if the participant believed that he/she was actively managing/coping with his/her diagnosis of lupus, 80 individuals responded (n = 80); and 67 (83.75%) said “yes” and 13 (16.05%) said “no.” Consequently, the average participant within this study was an active patient, with an above average level of readiness for self-directed learning, and believed he/she was actively coping with his/her diagnosis.

Table 3
Demographic Characteristics of Study Participants

Sample		
Ethnicity	n	%
Caucasian	48	59.26
African-American	18	22.22
Hispanic	13	16.05
Native American	2	2.47
Total	81	100
Gender		
Gender	n	%
Female	76	93.83
Male	5	6.17
Total	81	
Age		
Range (in years)	22 - 76	
Mean score (in years)	50.14	
Education	n	%
Below Secondary	1	1.23
High School Diploma	13	16.05
Some College	15	18.52
Associate's Degree	10	12.35
Bachelor's Degree	23	28.40
Master's Degree	14	17.28
PhD	4	4.94
Post Graduate	1	1.23
Total	81	
SDLRS (n = 81)		
Minimum	148.00	
Maximum	281.00	
Mean	229.49	
VPMI (n = 81)		
Minimum	29	
Maximum	61	
Mean	46.79	
Management Question	n	%
Yes	67	83.75
No	13	16.05
Total	80	

Results of Hypothesis Testing

Two research questions, converted to null hypothesis for statistical analysis, were used to guide this study. The findings for each are presented.

Research Question One. What is the relationship, if any, between the *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients? H₀₁: There will be a statistically significant relationship in the scores of self-directed learning readiness if a patient is defined by the *Vanderbilt Pain Management Inventory* as being an active versus passive patient.

Data from the sample of 81 participants who took: (a) *The Self-Directed Learning Readiness Scale*; (b) *The Vanderbilt Pain Management Inventory*; (c) the open-ended question regarding their perception of their health management status; and (d) met the criteria of having a positive, physician diagnosis of lupus was used to test research question one. To determine if there was a relationship between *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* a Pearson's r was performed.

It was determined that as a patient's abilities of *Self-Directed Learning Readiness Scale* score increases, her *VPMI* score decreases, meaning that her ability to be an active patient increases. There was a relationship in the scores of *SDLRS* if a patient was defined by the *Vanderbilt Pain Management Inventory* as being an active versus passive patient (see Table 4). A Pearson's r was computed to assess the relationship between *SDLR* and *VPMI* scores. There was a correlation between the two variables [$r = -.32$, $n = 81$, $p = .003$]. Further, a Cohen's d was performed to recognize effect size. The effect size was

determined to be moderate to large practical significance, at $d = .605$ with a 73 percentile standing. The effect size for this analysis ($d = .605$) was found to exceed Cohen's (1988) convention for a moderate/medium effect ($d = .50$).

Table 4

Correlations of *SDLRS* and *VPMI* Results

		SDLRS	VPMI
SDLRS	Pearson Correlation	1.00	-.32
	Sig. (2-tailed)		.003
	N	81	81
VPMI	Pearson Correlation	-.32	1.00
	Sig. (2-tailed)	.003	
	N	81	81

Research Question Two. What is the relationship amongst the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score? H₀₁: There will be a statistically significant relationship between the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score.

- a. Age will significantly affect the relationship.
- b. Education will significantly affect the relationship.
- c. Ethnicity will significantly affect the relationship
- d. Gender will significantly affect the relationship.

Data from the sample of 81 participants who took: (a) *The Self-Directed Learning Readiness Scale*; (b) *The Vanderbilt Pain Management Inventory*; (c) the open-ended question regarding their perception of their health management status; and (d) met the criteria of having a positive, physician diagnosis of lupus was used to test research question two. Multiple regression analysis was used to evaluate how well the variables of age, education, ethnicity, and gender predicted the self-directed learning readiness score.

- a. A multiple regression analysis was conducted to discern whether age and *VPMI* score affected the *SDLRS* scores. The hypothesis was rejected. The results of this analysis indicated that the total model accounted for a moderate to small (22%) amount of interaction, $f = .22$. Further, to determine effect size the square of the Pearson correlation r was calculated. $R^2 = .48$, thus establishing a medium to large effect size of practical significance.
- a. A multiple regression analysis was conducted to discern whether education and *VPMI* score affected the *SDLRS* scores. The hypothesis was rejected. The results of this analysis indicated that the total model accounted for a moderate to small (25%) amount of interaction, $f = .25$. Further, to determine effect size the square of the Pearson correlation r was calculated. $R^2 = .62$, thus establishing a large effect size of practical significance.
- b. A multiple regression analysis was conducted to discern whether ethnicity and *VPMI* score affected the *SDLRS* scores. The hypothesis was rejected. The results of this analysis indicated that the total model accounted for a moderate to small (13%) amount of interaction, $f = .13$. Further, to determine effect size

the square of the Pearson correlation r was calculated. $R^2 = .16$, thus establishing a small to medium effect size of practical significance.

- c. A multiple regression analysis was conducted to discern whether gender and *VPMI* score affected the *SDLRS* scores. The hypothesis was rejected. The results of this analysis indicated that that the total model accounted for a moderate to small (19%) amount of interaction, $F = .19$. Further, to determine effect size the square of the Pearson correlation r was calculated. $R^2 = .36$, thus establishing a medium to large effect size of practical significance.

Open-ended Question Results

Based on analysis of the data that resulted from the open-ended question responses, and the nature of this population, the participants demonstrated high levels of characteristics related to self-directed learning. In total, 25 codes were established, including active and passive coping measurements, the characteristics of self-directed learning readiness established by Guglielmino (1977), and themes pertaining to the participants' health-management perceptions. The open-ended responses provided insight into the awareness of the study's participants' self-health management abilities and level of coping. See Figure 4 for all of the themes and the number of appearance within the open-ended responses.

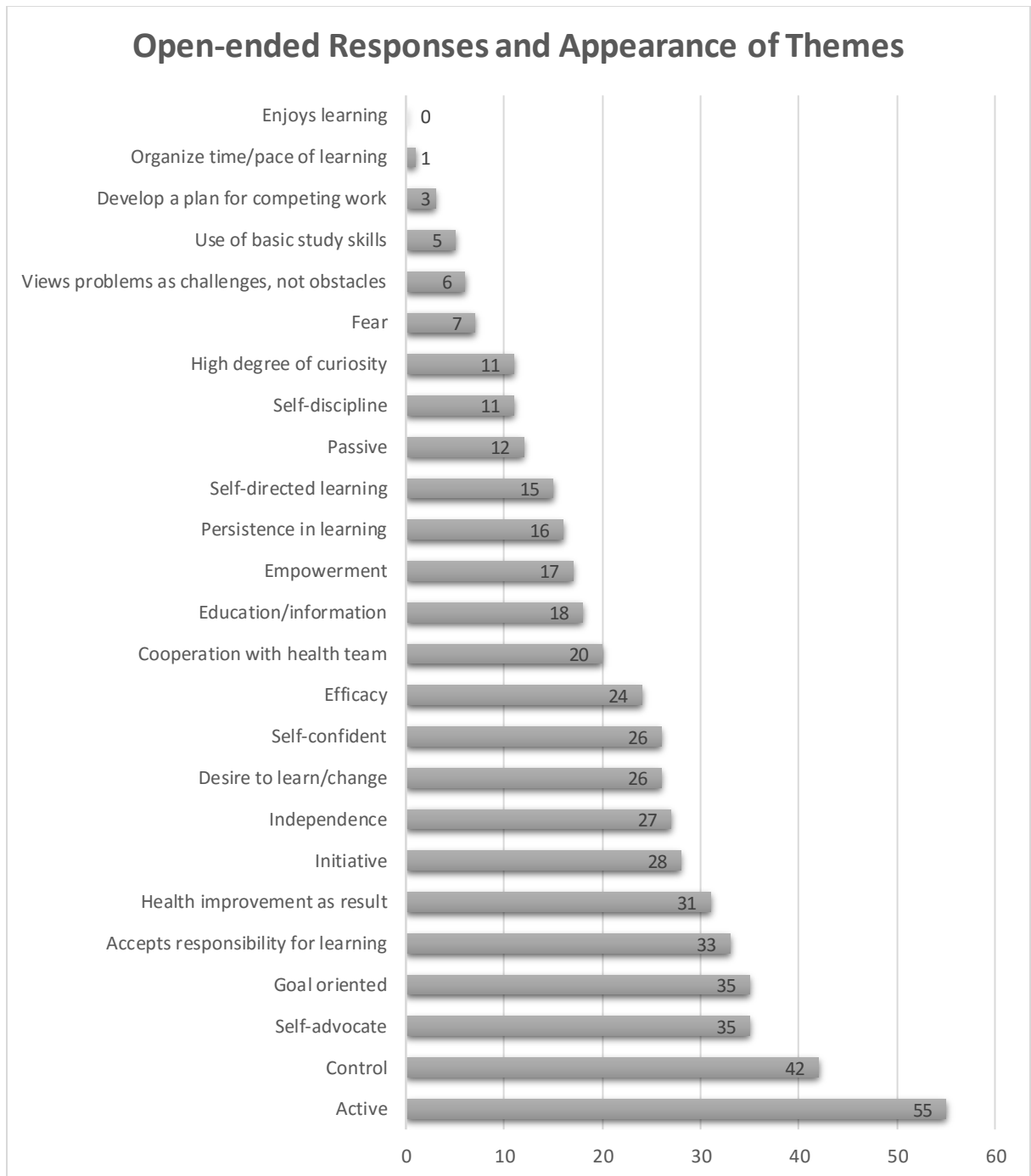


Figure 4. The codes generated from the open-ended responses.

The amount of appearance for each coded theme that was provided by the study's participants within the open-ended responses

Of the 59 responses analyzed in total, the characteristics most reflected within the study participants reactions pertained to coping capabilities. The themes associated to coping related to active and passive dimensions. However, elements that create the make-up of active coping and patient leaders were the most prevalent features of the open-ended responses. To illustrate the percentage of the themes occurrence within the data see Figure 5.

At 55 responses, 10. 91% overall, active coping was found to be the most prevalent theme that emerged within the study participants replies. Control, 8. 33% overall, was the next principle that emerged as predominant, which was found within 42 responses provided within the open-ended responses. Self-advocacy, at 42 of the 59 responses, represented 6. 94% overall, was the third largest theme that emerged amongst the data. Health improvement was the fourth largest theme (that was not related to self-directed learning) that emerged amongst the data with 31 responses, 6. 15% overall.

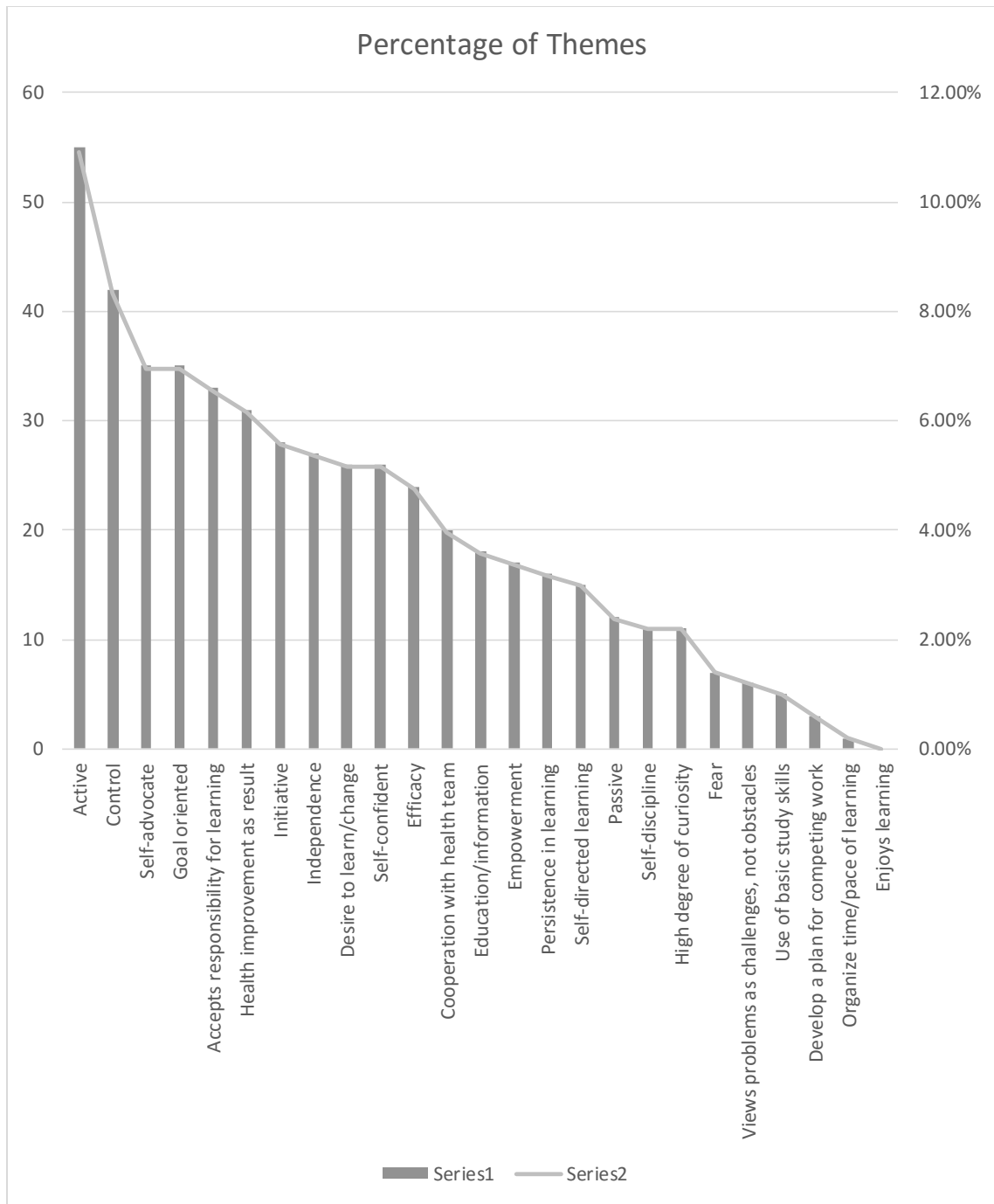


Figure 5. The percentage codes.

Percentage of the appearance of each coded theme provided by the study's participants within the open-ended responses

The characteristics of self-directed learning readiness most reflected were (a) goal oriented, with 35 responses, represented 15.35% of SDL characteristics overall; (b) accepts responsibility for learning, with 33 responses, represented 14.47% of SDL characteristics overall; (c) initiative, with 28 responses, represented 12.28% of SDL characteristics overall; (d) independence, with 27 responses, represented 11.84% of SDL characteristics overall; (e) desire to learn/change, with 26 responses, represented 11.40% of SDL characteristics overall; and (f) self-confidence, with 26 responses, represented 11.40% of SDL characteristics overall. See the Figure 6 below for themes, number of responses in which they emerged in, and their percentage of occurrence amongst self-directed learning characteristics.

Minimum codes were found for some characteristics of self-directed learning: (a) views problems as challenges and not obstacles, with only 6 responses; (b) use of basic study skills, with only 5 responses; and (c) organize time/pace of learning, with only 1 response. In some cases the individuals were so overcome with the disease, mentally and/or physically, that the ability to plan educational pursuits regarding the illness was not the point, but information for the sake of survival was. The individuals acknowledged that the chronic disease took over their lives and little planning was evident. No evidence of the characteristic related to the enjoyment of learning emerged amongst the data. See Table 5 for specific examples of responses representative of themes coded within this study.

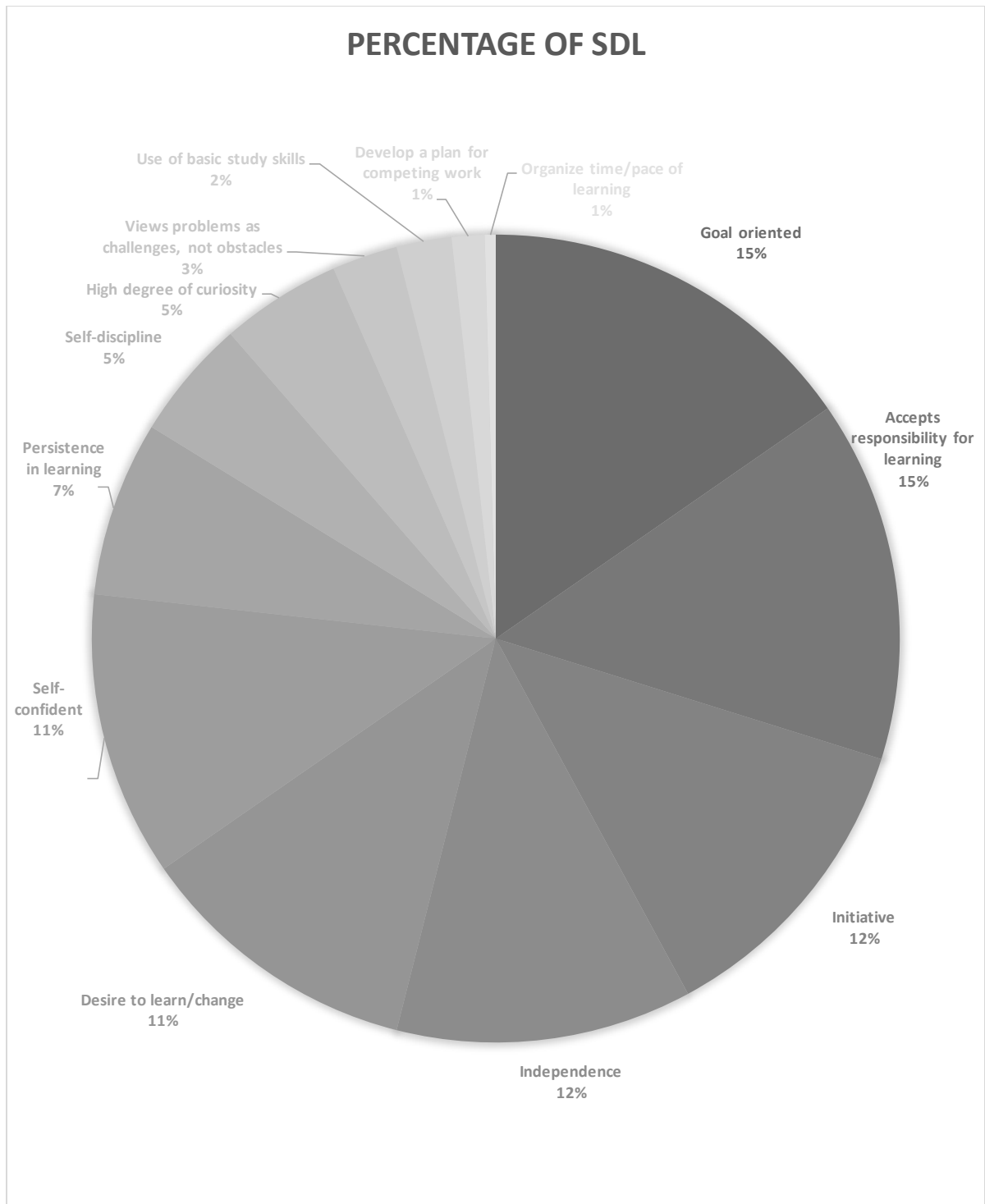


Figure 6. The percentage of SDL themes.
 A graphical illustration of the percentage of self-directed learning readiness characteristics and themes that appeared within the open-ended responses provided by the study's participants.

Table 5

Sample of SDL Characteristics from the Open-Ended Responses

ID	Responses	Themes and Self Directed Learning Characteristics
Question: Do you believe that being actively involved in your healthcare affects your health management? Please explain.		
A001	“Yes, when a patient is actively involved in their healthcare then it improves their health management and health outcomes because they are better informed and more knowledgeable and can better work with their healthcare team to develop effective treatment plans.”	Active, Education, Control, Initiative, Persistence, Accepts responsibility for learning, Desire to learn/change, Develop a plan, Goal-oriented, Health improvement as a result, Cooperation with health team
A003	“Yes, because you are making a conscious decision to become involved on how to treat and manage your health/ health plan and not leaving it entirely to the doctors or insurance/ medical coverage to decide what is best for you. Sometimes, you’re your best doctor, in that you know what your body is feeling, what it needs, and what it can handle.”	Active, Self-directed, Control, Initiative, Independence, Persistence, Accepts responsibility for learning, Self-discipline, Develop a plan, Goal-oriented, Health improvement as a result, Cooperation with health team
A007	“Yes. It’s my life and my body. Who else is going to do it? Other people have no way of knowing how someone feels.”	Active, Self-advocate, Control, Initiative, Independence, Accepts responsibility for learning, Desire to learn/change, Self-confident
A010	“Yes. You need to be responsible for yourself.”	Active, Control, Self-advocate, Independence, Accepts responsibility for learning, Desire to learn/change, Self-discipline, Efficacy

Table 5 Continued

ID	Responses	Themes and Self Directed Learning Characteristics
A021	<p>“Being actively involved and working with my ‘rhuemy’ helps us both to understand which medications are helping the best for me. Being competent enough to understand the effectiveness of the meds. and researching what they can do helps me decide if I really want to use that medication. I am lucky enough that all my doctors’ work together to make sure that any meds. they decide to give me doesn’t interfere with my current meds. If I wasn’t competent enough, or didn’t show my list to each doctor- I could end up with a big problem- also working in the medical field had given me more knowledge than most.”</p>	<p>Active, Self-directed learning, Self-advocate, Education/information, Control, Persistence in learning, Accepts responsibility for learning, Views problems as challenges and not obstacles, Desire to learn/change, Self-confident, Use of basic study skills, Develop a plan for completing work, Goal-oriented, Health improvement as result, Cooperation with health team, Efficacy, Empowerment</p>
A025	<p>“Yes. I believe the more information I have the better I can identify and manage symptoms.”</p>	<p>Active, Self-advocate, Education/information, Control, Persistence in learning, Accepts responsibility for learning, Views problems as challenges and not obstacles, High degree of curiosity, Desire to learn/change, Self-confident, Goal-oriented, Health improvement as result, Efficacy</p>
A052	<p>“I’m newly diagnosed; positive ANA and positive PANCA. I have not received one specific diagnosis and do not have medical coverage in Florida, but do in New York- where I’ll soon return. As of June last year, I went from hiking mountains—to not being able to ride a bike around the block. I think it’s getting ahead of me and moving too fast for me to get a handle on. I’m not working and probably could use disability.”</p>	<p>Passive, Fear</p>

Table 5 Continued

ID	Responses	Themes and Self Directed Learning Characteristics
A072	“Sometimes it feels like no one hears me; or I should get used to it.”	Passive, Fear
A088	“Yes. I believe it helps to keep your health under control.”	Active, Control, Accepts responsibility for learning, Goal- oriented, Health improvement as result
A094	“Absolutely. But it is hard at times because physicians of each specialty have a piece of your disease. Getting them all on the same page is tough. And being honest is hard because of fear of being cast as a crybaby.”	Active, Passive, Cooperation with health team, Fear

Chapter Summary

This chapter presented the findings from the *Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness* study. Descriptive statistics were presented, research questions one and two were answered, and self-directed learning characteristics were examined through the responses to the open-ended question.

Research question one proved to be significant and determined that self-directed learning positively influenced an individual's ability to be an active patient. Hypothesis one was correct.

Research question two proved to be insignificant. The demographic characteristics of age, ethnicity, education level, and gender did not have a direct relationship between self-directed learning readiness and active/passive coping groups. Hypothesis two was rejected. Further, it was found that the majority of the participants within the study, 83.75%, considered themselves an "active" patient managing their lupus diagnosis. In direct contrast, 16.05% of the participants did not believe that they were actively managing their illness.

Through the responses provided on the open-ended question the two most prevalent themes emerged pertained to active coping and control. Characteristics of self-directed learning readiness appeared predominant amongst the responses as well, particularly goal-orientation and accepting responsibility for learning. Minimal themes regarding planning and enjoyment of learning were provided within the data.

V. DISCUSSION, CONCLUSIONS, RECOMMENDATIONS

“Good health is a crown worn by the healthy that only the ill can see.”

-Arabic Proverbs

Study Overview

Chronic illness is an epidemic reeking disastrous effects, physically and mentally, on not only the patient, but their caretakers, family, friends, community, and society as a whole. Of the “45 percent of the American population” that now has one or more chronic conditions, “almost 30 percent of these individuals have sufficient disability to limit their normal daily activities” (Funk & Tornquist, 2001, p. 3). The management of chronic illness is, by its very nature, a process that involves multiple players over an extended period of time.

Because many health problems involve multiple, intertwined medical and social causes, efforts to prevent and manage chronic illness will require change at “level of families, social networks, organizations, and communities” (Cronenwett & Leeman, 2001, p. 381). As emerging chronic diseases are being manifested due to individuals living longer, there are also internal, external, environmental, and lifestyle factors that contribute to the stark rise in chronic disease. Some can be remedied through personal regime changes, but many cannot.

Lupus is an autoimmune, chronic illness that receives very little scholarship, funding, and research; despite the fact that the effects of the disease can range from a lowered immune system to death. The mysterious nature of the disease demands more investigation. Due to the fact that lupus is not one of the chronic diseases that can be managed or “controlled” with lifestyle changes, in order to fulfill the void in research, and to positively impact lupus patients’ quality of life, an exploration into the relationship between education and health needs to be analyzed.

The notion that education has an impact on health is not new. However, the dire need to understand the relationship and further that impact is. As the United States’ healthcare system becomes more complex and individuals are being expected to be more actively involved in their healthcare management, many barriers arise. With escalating healthcare and insurance costs, and despite acknowledgement of such, there has been “limited improvements in the overall health of the population,” (Frank, 1999, p. v) which have resulted in “decreased public confidence in the American healthcare delivery system,” (Frank, 1999, p. v). Now more than ever before, there is a “new emphasis on outcome measures” (Frank, 1999, p. v). Limited health literacy, the complexity of health information-related materials, costs, access to healthcare, and didactic, hierarchal relationships between healthcare providers and patients are just several obstructions thwarting an individual’s successful health management.

So, what is the answer? Education. Education and implementation of adult learning strategies within the healthcare field and patient self-management strategies may help. The literature that is available shows that being a better informed patient positively

impacts health care. Adult learning occurs in any context and can aid individuals within ever-changing and challenging life situations, including health management in particular.

Self-directed learning is a predominant tenet of adult learning. Active coping/managing of one's chronic illness is crucial to successfully living with a chronic disease. This is especially true considering the devastating and varying nature of chronic illness, and more specifically, that of lupus.

However, simply implying that there is a relationship between education and health is not enough. It is no longer sufficient to just recognize the need for interdisciplinary and cross-disciplinary work. If chronic disease manifestation cannot be prevented, at best, it needs to be managed actively; and this goes beyond the spectrum of biological science. Social, behavioral, medical, biological, and educational fields are all indicted within the care of chronic illness.

“The major causes of morbidity and mortality in society have a strong behavioral component. Research has clearly demonstrated that lifestyle behaviors are amendable to change through community and individual health promotion and disease prevention” (Funk & Tornquist, 2001, p. 5). With further review of the research, according to Hill (2001), there is “a gap between the efficacy of interventions in studies and their effectiveness in practice” (p. 12) and “one reason for the gap is between research and practice is that the bulk of the funding spent on biomedical research has been spent on basic research” (p.13).

This implies that once the studies are done, that is often the end of the research. Thus, research

often languish in the scientific literature, unread and unused in practice. In part, that is because the research is scattered across disciplines and journals, and articles often lack the specificity needed to guide implementation. Further, there is a little examination of issues of applicability and implementation. (Funk & Tornquist, 2001, p. 3-4)

Nevertheless, this is the point where adult education is most useful. There is a need to turn research into application and practice. Hill (2001) continues by stating:

we are not going to successfully prevent chronic illness if we do not look at the full continuum of sciences from the laboratory science to the clinical and community sciences. It is not enough to do research and publish statements about what people need to do; we also need to look at whether people are aware of those statements or those research findings and whether they lead to behavior change [...] It is critical to increase people's awareness, knowledge, motivation, and skills related to behavior change. (p. 15)

It is through the recognition and further development of community education programs, such as the support groups and seminars exemplified within this study, that research is transformed into practice. Furthermore, studies of this nature has the potential to not only add to the body of knowledge, but further the potential of these interventions to model and supply behaviors to enable individuals to actively manage/cope with his/her disease.

By analyzing specific data collected from individuals with a positive diagnosis of lupus, this study, *Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness*, presents documentation of self-directed learning in health education, self-directed learning in the context of one's own personal

health management, and proposes self-directed learning as a solution to the numerous barriers to personal health education. Furthermore, the data analyzed supports the theory and importance behind the notion of being an active patient, one who is engaged with their own healthcare management. Versus a passive patient, an individual who views the doctor as the sole person in charge of one's health status. Ideas regarding future research needs and program implementation within the community setting are also included.

The purpose of this study was 1) to examine the significance, if any, of a patient's active or passive role in terms of his/her health management; 2) to determine if a relationship existed between his/her active and passive scores and his/her self-directed learning readiness, and 3) to identify if his/her view of one's self as a patient (when diagnosed with a chronic disease) impacted his/her own personal health management. Quantitative analysis of two specific instruments, *The Self-directed Learning Readiness Scale* and the *Vanderbilt Pain Management Inventory*, was used to measure a patient's self-directed learning readiness and his/her ability to manage and/or cope with a positive diagnosis of lupus.

Also, the patient's approaches to learning and personal characteristics were analyzed and compared to the characteristics associated with the elements of self-directed learning. Furthermore, the researcher has identified self-directed learning elements that are essential for patients to actively manage/cope with his/her chronic illness.

These characteristics are identified to further the research and program implementations that will help to develop leadership abilities and activity levels of self-health management in chronically ill patients. Research shows:

effective chronic illness management requires an appropriately organized health care system linked with necessary policies and resources in the broader community. These policies and resources may provide access to critical supportive or educational services otherwise unavailable in health care systems.

(Wagner, Davis, Schaefer, Korff, & Austin, 2001, p. 289)

Two research questions guided this study. (1) What is the relationship, if any, between the *Self-Directed Learning Readiness Scale* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients? (2) What is the relationship amongst the *Vanderbilt Pain Management Inventory* and the demographic characteristics of age, ethnicity, education level, and gender on the *Self-Directed Learning Readiness Scale* score?

Discussion of Findings and Conclusions: Research Questions

The results from research question one showed that the more self-directed an individual was the more likely he or she was to be an active patient. This relationship suggests that self-directed learning is essential to successfully managing one's health and to actively cope with a chronic illness. "Successful self-management is based on a collaborative process between patients and providers to define [a] problem, set priorities, establish goals, create treatment plans, and solve problems along the way" (Wagner et al., 2001, p. 291).

The finding illustrates the underlying connection between adult learning and health. It further exemplifies the application of adult learning strategies within one's life. Also, the data is evidence of self-directed learning principles actively enriching adult learners' lives.

The data clarifies that self-directed learning occurs within a variety of settings, including informal educational situations, at any time, using a variety of methods. The mean score of the study's participants, determined by the *Self-Directed Learning Readiness Scale*, was 229.49, with ranges from 148.00 to 281.00.

According to Guglielmino (1977) the average adult mean score is 214. Placing the individuals in this study at an "above average" level of readiness for self-directed learning (Guglielmino, 1977). This finding supports the literature and concept behind the "passive" patient who needs more traditional forms of educational settings and deliveries; which mirrors the way the passive patient receives or views healthcare. This finding also explains why the didactic, hierarchal relationship of health provider residing over the patient's healthcare is supported and/or expected in the passive setting.

In opposition, persons with high levels of readiness for self-directed learning tend to have "a high degree of problem solving abilities," "a high degree of creativity," and "a high degree of change" (Guglielmino, 1977). According to Wagner et al. (2001), medical practitioners and organizations do provide patients with some sort of education to assist with self-health-management, but "most depended on traditional, information- oriented resources" (p. 297), which is in direct conflict with how individuals with a high level of self-directed learning readiness receives, evaluates, and applies information. "Persons with high SDLRS scores usually prefer to determine their learning needs and plan and implement their own learning" (Guglielmino, 1977), and this explains why these same individuals are more actively managing his/her healthcare.

The past several years have seen an explosion of "disease management" efforts directed at major chronic illnesses. The movement has been fueled by the struggle

to find how to best care for patients with chronic illness in an era of cost constraints and performance expectations imposed by purchasers. Recent surveys have documented the intensity of the efforts (National Managed Health Care Congress, 1996) without, however, providing much evidence as to the characteristics and quality of the programs or the effects on patients. (Wagner et al., 2001, p. 289)

With further research into the successful use of self-directed learning and health management, quality evidence can be provided to support the creation of community wide programs and implementation of health seminars focused on cultivating self-directed learning readiness within persons diagnosed with a chronic illness.

Through this type of patient development and emphasis on self-healthcare management, “the aim is to support the development of informed, activated patients and prepared, proactive, professional practice teams” (Wagner et al., 2001, p. 290). This further supports the creation of the patient leader because “effective self-management support helps patients and families cope with the challenges of living with and treating chronic illness” (Wagner et al., 2001, p. 291).

The results from research question two showed that age, gender, ethnicity, and education level did not have a large impact on the relationship between the *Self-Directed Learning Readiness Scale* scores and the scores on the *Vanderbilt Pain Management Inventory*. This finding illustrates the impact of being diagnosed with a chronic illness. It is not the demographic characteristics that encourage the necessity for self-directed learning or active coping. Education, gender, age, and ethnicity had no bearing on a

person's self-directed learning readiness. Instead, it is the diagnosis of a chronic illness that encourages and creates the need for self-directed learning and active coping.

This supports the indication that it is not demographics that are important for an individual to manage/cope with his/her disease, it is the strong *need* that overcomes an individual when diagnosed with a chronic illness that is important. This finding is further magnified, and becomes even more important, when it is considered that the likelihood that individuals who suffer from one chronic illness will more than likely be diagnosed with at least one other in their lifetime.

Multiple chronic illnesses creates an even bigger demand for self-directed learning and active self- health management. According to Lorig (2001), there is now “strong evidence that it is possible to teach self-management skills and to improve self-management. Such improvements lead to improved health and lower health care utilization” (p. 41).

Discussion of Findings and Conclusions: Self-directed learning characteristics

Minimal data related to the planning of, enjoyment, and ways of learning emerged amongst participant responses. Specifically, “use of basic study skills, the determination to “develop a plan for competing work,” the “organization of time/pace of learning,” and the “enjoyment of learning” had less than a 2% impact on the overall responses. By not being a priority to the participants, this further supported the importance placed on active coping and other more relevant self-directed learning readiness characteristics (such as being goal-oriented and persistent). The majority of the individuals acknowledged that the emergence of the chronic disease is what forced them to become active within their health management. With the initial crisis experienced by persons when first diagnosed

with lupus takes precedent in one's life. Thus, "developing a plan" and "enjoyment of learning" was not the primary focus of their learning endeavor, survival was. Rather, in many responses, the patient mentioned initiating plans in coordination with their healthcare provider in order to seek out health improvements.

Initiative, Persistence, Self-efficacy, and Behaviors

Research by Weiss (2001) suggests that the effectiveness of health programs "appears to depend on the willingness of the individuals to accept responsibility for initiating and sustaining health behaviors" (p. 174). "Initiative" and "persistence" (sustaining behaviors) are two characteristics also found in self-directed learning. Furthermore, individuals who wish to incorporate the proper healthcare management behaviors must be capable of self-directed learning in order to acquire new behaviors and to learn how to perform, apply, and sustain them.

Patients' competence to perform the behaviors is termed self-efficacy (Bandura, 1986), another theme that emerged amongst the participants responses, accounting for almost 5% of total responses. Self-efficacy varies and depends on the context and person, furthermore, it fluctuates. "Self-management is crucial to positive outcomes, as is self-efficacy" (Champagne, 2001, p. 51).

There are four primary methods of enhancing self-efficacy or perceived confidence: inactive attainment, vicarious experience, verbal persuasion, and physiological state (Corbett, 2001). Stuijbergen et al. (2001) suggests:

while state-of-the-art disease-directed care and treatment should be pursued, this study suggests that attention should also be directed to maximizing health-promoting behaviors. The continuing increase in the number of persons with

chronic, disabling conditions make it imperative to explore strategies to help these people identify and maximize their resources, develop their self-efficacy for health behaviors, and enhance physical activity, nutrition, stress management, and spiritual growth in order to maintain quality of life. (p. 204)

Patients diagnosed with a chronic disease who illustrates self-efficacy use better care practices and have better outcomes. Thus, developing initiative, persistence, self-efficacy, and health promoting behaviors is essential to actively coping and creating a better quality of life for individuals suffering from chronic illness(es).

Goal-Oriented, Accepts Responsibility, and Desire to Learn/Change:

Fear and Support Groups

Fear, worry, and regret were emotions that emerged amongst the participant responses. These responses can also be commonly found amongst the literature. According to Lahita and Phillips (2014), lupus can be the source of anxiety, depression, regret, guilt, and monetary concerns. Uncertainty regarding one's future, including treatment, social relationships, and symptom development often accompany a positive diagnosis. "Often, however, the main source of anxiety is lack of knowledge about the disease, as mentioned earlier, so it makes sense to learn as much as you can" (Lahita & Phillips, 2014, p. 272). Again, self-directed learning is espoused as a remedy to specific negative situations and occurrences, such as flare-ups and new symptom development, pertaining to one's diagnosis. Furthermore, another recommendation to overcome negative emotions and to actively cope with lupus is to take part in support groups. Lahita and Phillips (2014) advise patients that:

support groups can play a very important role in living with lupus. People may find groups helpful so that they don't feel as isolated as before. Participants can share their feelings of frustration, anger, or guilt. A good support group can be helpful in providing facts and suggestions to help people to better cope with lupus. (p. 275)

Higgins and Leibowitz (2001) explicates further by conferring the coping advantages offered by social support, such as support groups, or as they are known within the field of adult education as communities of practice (CoP). These groups provide members with frame of references to "evaluate reality" and "standard performance" (Higgins & Leibowitz, 2001, p. 32). Further, it is believed that "exposure to individual suffering from serious illness or disability raises awareness of one's own mortality or vulnerability, it should also motivate efforts to seek relief from the resulting discomfort" (Higgins & Leibowitz, 2001, p. 32).

The Role of Communities of Practice, Social Support, and Support Groups

The development of support groups, through private organizations such as The Lupus Foundation of America, Inc. and The Lupus Foundation of Florida, incorporate many processes and practices that are used by patients to assume a more self-directed approach to their own health care. There are specific qualities that create a community of practice which include emerging problems, such as a chronic illness, and an exchange of experiences, which is frequent amongst peer support groups focusing on such illnesses.

They are often informal, usually taking place within community settings, similar to the sites analyzed within this study. Self-directed learning and peer support are essential to managing and coping with a chronic illness. The creation of such groups is in

itself a recent phenomenon exemplifying patients whom are taking a more active and self-directed approach to the management of their own health care.

Communities of practices take many forms and are created by adult learners with common interests, experiences, and a shared quest for knowledge. All community of practices have some things in common. The most predominate characteristics are that they involve self-directed learning by individuals, as well as group learning through each other's' experiences and interactions (Hansman, 2008, p. 294). Patients learn through sharing experiences and exchanges with other patients. This method of involvement is examined through the reflections and the creation of community of practices, in the form of support groups and social support.

Peer support is so effective in part because of its non-hierarchical reciprocal relationship created through the sharing of experiences and knowledge with others who have faced or are facing similar challenges. This exchange promotes mastery of self-care behaviors and improves disease outcomes. In addition, people often learn better when they are taught by peers with whom they identify and share common experiences (Heisler, 2006, p. 8).

Communities of practice and support groups are created from a social fabric. Patients create meaning and gather knowledge through interaction with individuals suffering a similar plight. Through interactions, support groups transform into a group of practitioners with a network of common assumptions and learning needs. Thus creating a group of patient advocates and leaders.

The virtual community of practice gives patients with chronic illnesses a way to communicate, share experiences, and learn from other patients. One such patient writes:

“Yes. [Being actively involved in my healthcare affects my health management.] I realized at the start of my diagnosis I was very uneducated and really didn’t know what was happening to me and could have died. I made it a priority to become educated about lupus and how it affects me. Now I feel very empowered and I read everything I can on how to manage my health care and I apply it and have seen results. I am responsible for me.”

Another participant states:

“Yes, [Being actively involved in my healthcare affects my health management.] I read everything I can about autoimmune illnesses, especially lupus. I am actually in a support group and attend several seminars each year.”

By just these single responses, insight into the patient’s self-directed characteristics defined by the researchers of “initiative, independence and persistence in learning, as well as a strong desire to learn or change” is provided. The innate self-directed nature of the community practitioners is evident by their organization surrounding a shared goal. These individuals are taking the initiative to define their own learning needs, create their own learning objectives, and are not only sharing resources and tools with other patients, but their very own experiences act as resources as well. These functions are integral parts of successful communities of practices (Hansman, 2008, p. 301).

CoPs, Health Improvement, and Cooperation between Health Team and Patient

Another relevant finding that emerged from the data was the participants’ lack of information or engagement with their medical practitioners. This is what led to the need for self-directed learning and social support in the form of communities of practices that

were developed within support groups. The need for peer support was also reinforced within the literature:

A 2003 World Health Organization report argued that improving patient chronic disease self-management would have a far greater impact on the health of the population than any improvement in specific medical treatments. [...]

Interventions that mobilized and build on peer support are especially promising ways to improve self-management support for patients with chronic conditions.

(Heisler, 2006, p. 7)

Thus, through social support an individual can create, cultivate, and learn firsthand experiences on how to construct better cooperation with their medical team and have improved health outcomes and behaviors as the result. Through peer interaction and social support, persons diagnosed with chronic disease can emphasize healthier behaviors and shared experiences.

This finding is significant because often times patients leave their physicians with unanswered questions and more frustrations. Large medical words, unfamiliar jargon, and unanswered questions force patients to seek out answers on their own. Predominately through resources regarding patient information, either from patient materials, medical explanations on the internet, and/or individuals suffering from the same diagnosis. After examining several documentations, through the open-ended question responses, for personal health management strategies it became clear that self-directed learning approaches within support groups and communities of practice created a more positive impact between patient and medical team engagement.

Many responses analyzed illustrated the patients desire to positively communicate with their physicians and gain results that would lead to more positive health-related outcomes. To elucidate, one participant stated:

“My care is split over so many specialists and my symptoms can be general or vague. So if I am not extremely active in compiling information from specialists and trying to figure out solutions on my own, nobody will do it for me. There is little to no coordination of care among specialists and almost every appointment results in a referral to another specialist. To manage costs in specialist co-pays and demands on my time/energy, I have to know enough to prioritize specialist referrals and focus on one treatment option at a time.”

The self-directed mentality of the participants results in equipping other community members with better ways to engage with their medical team. One participant explicitly mentions attending support groups:

“I read everything I can about autoimmune illnesses, especially lupus. I am actually in a support group and attend several seminars each year.”

Novel Finding: Sense of Empowerment and Control

The investigation into the creation of communities of practices within lupus support groups and the connection with patient health improvement lead to a novel finding: a sense of empowerment and control within the participants. Because of the varying nature of lupus, and its ability to have devastating ailments, at some point, most patients communicate feeling a lack of control over one’s life and the sense of powerlessness that is attached to those thoughts. But this study shows that being more self-directed in nature can help eradicate those feelings.

Lupus has the ability to be a destructive force. There are no other treatment options besides medication (which can also wreak havoc on a person's body, in addition to directly causing depression because of side effects) and active coping. There is no cure. In actuality, it is the symptoms of lupus that are being treated and not the actual disease, since the definitive cause is still unknown. Like all other chronic illnesses, lupus is a lifelong companion with varying levels of activity throughout one's lifespan. The devastating and varying nature of the disease can make many individuals suffering from lupus feel uncertain and like they have a strong lack of control within their lives. For example:

Daily activities are affected by lupus pain, insomnia, extreme fatigue, depression, the unpredictability of lupus medication, its side effects, and poor body image. These problems can lead to lower self-esteem and mood swings. Many people with lupus have much greater difficulty taking care of themselves or their children. (Lahita & Phillips, 2014, p. 255)

Further, disease activity level usually requires lifestyle changes and a sense of identity loss for the patient:

In addition, many people with lupus look well, so others have a hard time believing they are really sick. Some people lose friends because they often have to cancel appointments at the last minute. People with lupus may become depressed because of difficulties carrying out the accustomed roles. (Lahita & Phillips, 2014, p. 269-270)

Lupus affects every aspect of one's life. As a result of the disease many persons' suffering from lupus are left feeling enslaved to the disease. However, by becoming a

more self-directed learner and an active patient, individuals can regain a sense of control which leads to feelings of empowerment. This transformation in feelings of negativity to positivity can lead to better outcomes and improved health behaviors. Lahita and Phillips (2014) state that “it is helpful in guiding patients to learn methods of coping with their illness and to gain a sense of control by using preventative or improvement strategies” (p. 202). In recognition of this there has been a surge in interest, awareness, and understanding regarding coping; and, it is believed that “most instances of coping responses are within our awareness” (Snyder & Dinoff, 1999, p. 6).

A novel finding that emerged amidst the data was the sense of empowerment and control that the participants felt through being an active patient, managing one’s health, and using self-directed learning to create better outcomes and healthier results. Themes regarding being an “active patient” was recognized 55 times, “control” emerged 42 times, and “empowerment” was mentioned 17 times. The prevalence of these themes illustrated that being an active, highly self-directed patient leads to an individual feeling more in control over his/her life. Further, this level of control leads to feelings of empowerment within the patient. Through knowledge attainment, by providing a way for individuals to govern one’s own wellness management or research symptom remedies, self-directed learning provides the patient with access to navigate and take control over parts of one’s life that once seemed uncontrollable. In Table 6, specific participant responses that illustrate this unique finding are provided.

Table 6

Sample of Open-Ended Responses in Support of Novel Finding

ID	Do you believe that being actively involved in your healthcare affects your health management? Please explain.
A001	Yes, when a patient is actively involved in their healthcare then it improves their health management and health outcomes because they are better informed and more knowledgeable and can better work with their healthcare team to develop effective treatment plans.
A002	Yes. Active involvement increases my control of my health care objectives.
A003	Yes, because you are making a conscious decision to become involved on how to treat and manage your health/ health plan and not leaving it entirely to the doctors or insurance/ medical coverage to decide what is best for you. Sometimes you're your best doctor, in that you know what your body is feeling, what it needs, and what it can handle.
A007	Yes. It's my life and my body who else is going to do it. Other people have no way of knowing how someone feels.
A008	Yes, it gives me a better understanding of what is going on with me. What I can do and what my doctor can do for me.
A015	Yes. I realized at the start of my diagnosis I was very uneducated and really didn't know what was happening to me and could have died. I made it a priority to become educated about lupus and how it affects me. Now I feel very empowered and I read everything I can on how to manage my health care and I apply it and have seen results. I am responsible for me.
A020	The more I learn about lupus, I feel that I can take control of my illness. Learning is the key of being healed from any illness.
A026	Yes, being involved keeps me aware of all of my symptoms and activities and dieting intake. Being involved keeps me healthy. Being involved also means eating and learning to prepare home cooked meals.
A078	Yes. Being aware and up to date as well as actively involved in your own healthcare contributes to a more positive outcome. Staying positive and involved in life also contributes to better health. Maintaining a well-balanced diet and exercise plan can alleviate pain and minimize stress, too.
A062	Yes we know our bodies best... Most people don't truly know how we feel... Lupus problems seem to be different everyday... It's like living death...

Table 6 Continued

ID	Do you believe that being actively involved in your healthcare affects your health management? Please explain.
----	--

A028	I want to know all I can about every test I have, every treatment available, and everything I can do on my own to feel the best that I can.
A029	As a patient you are your best advocate.
A034	Yes, I believe you own your own position in life, it's your responsibility not others to care for yourself.
A035	Yes, because I have a feeling of control. From prior experience, nurses and doctors have make mistakes and because I am proactive I can catch the errors.
A038	Absolutely! You are the only one who knows your body so you have to have a partnership with your doctor. I research and find a great deal of information about lupus and rely on the doctors to answer my questions so I can be knowledgeable about my conditions. The medicines being prescribed have side effects so I have the final say of what I take and how much.
A041	Absolutely! I can tell my physician about me, but I am still the only one who really knows me. I know what works, what does not, and what I am/ am not willing to try.
A042	Absolutely believe being actively involved empowers us to take control and manage the illness, even knowing there is no cure, there is management and control that is vital to our wellbeing.
A046	Yes, it's my health, my body, my life.
A048	Yes, understanding, researching, asking questions gives me the ability to make appropriate decisions.
A053	Yes I feel better when I am actively involved in my healthcare.

Researcher's Observation, Future Studies, and Recommendations

“He who has health, has hope; and he who has hope, has everything.”

-Arabic Proverb

After visiting many data collection sites that were essentially an open forum for persons and their caregivers affected by lupus to share information, air grievances, seek advice, and identify with other individuals suffering from the same condition, it was clear how vital these communities of practices are. Two important considerations were extracted through observation of these support groups and seminars: (1) the importance of developing a sense of empowerment and control as essential to successfully managing one's health and (2) the value of attaining more accurate information regarding chronic, autoimmune disease and the drastic need for this information and support to be espoused throughout the population.

When asked to participate in the *Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness* study, participants were beyond eager to take part. Expressions of empowerment and control were espoused by this specific population.

There are two underlying assumptions to account for this eagerness. As stated earlier on, the majority of the American population does not know what lupus is. Thus, many individuals who suffer from lupus come across issues of general acknowledgement and acceptance from the public regarding their disease.

Individuals that suffer from lupus have become a marginalized group. Analysis of research shows that the majority of studies and public campaigns regarding chronic illnesses are devoted to more *popular* illnesses. Take for example, breast cancer. Professional sports teams wear pink shoes, play with pink sporting equipment, or take part in public service announcements. Campaigns for *save the boobies, save the ta-tas*, and men's shirts that have expressions such as *I love boobs* or *big or small I love them all*

printed on them in support of breast cancer awareness are everywhere. In fact, the month of *October* is known as *Pinktober*. A quick google search promises over 37, 200, 000 results regarding breast cancer awareness. However, a quick google search on lupus awareness only results in about 3, 380, 000 outcomes. Just as breast cancer can wreak havoc on minds, bodies, and spirits, so can lupus. But what sports teams are wearing purple shoes or playing with purple footballs? Where are the national public service announcements? Why did May, which is lupus awareness month, go unnoticed?

Again, as one of America's most prevalent and devastating diseases, the lack of awareness and research is outstanding. Most lupus patients suffer silently. Their pain and experiences go unrecognized. Further, the majority of the studies that are conducted are clinical in nature. According to the Lupus Foundation of America (2013) the largest amount of research conducted are in biotechnologies and pharmaceuticals. Scientific investigations regarding health outcomes are regulated to numbers and bio markers instead of quality of life and emotions. In this light, patients are not seen as people or as individuals who are suffering. Instead, patients are viewed as empirical data. There seems to be a disconnect between science and reality. In turn, this made participants eager to be *a part of a study* that houses potential impact to notify the public regarding lupus.

Further, many participants expressed the idea that just filling out a survey provided them with some sort of locus of control. Again, feelings of empowerment were expressed by participants during the data collection phase. This suggests that future studies regarding patient empowerment and the patient leader need to be explored to enable individuals to transform their diagnosis from a crisis to an opportunity.

Since the few studies regarding lupus is mostly scientific in nature, the fact that there was interest in researching the *actual person* inflicted with this disease was exciting and empowering for the participants of this study. Individuals with lupus not only have to navigate the uncertainty of life that every person is presented with, but they must also do so with extended burdens. The varying nature of lupus and disease activity make navigating life even more difficult. Again, that high level of uncertainty can lead to feelings of loss of control. However, as exhibited during the data collection phase, having a voice and the ability to provide direct feedback implicating one's own feelings and perception of health management was rewarding and empowering. A voice was given to the voiceless. Thus, the option to participate in the study became a therapeutic opportunity and was established as a catharsis for this marginalized group.

To further exemplify these two notions, a group supported by the Lupus Foundation of Florida located in a rural area of Apopka, Florida is illustrated. Within this setting, it was clear that further edification regarding chronic illness, specifically lupus, is necessary. The demographics of the support group consisted of African-American women ranging from over the age of 30. At the time of data collection, it was discussed by the participants that there was an incorrect confusion held by the African-American community within Apopka that lupus, due to its autoimmune component, was related to acquired immune deficiency syndrome (AIDS). Because of this incorrect association, the participants of this group discussed feelings of shame and the secretive nature of what other African-American individuals diagnosed with lupus undergo. Again, participation within the study provided a voice to the voiceless. This occurrence resulted in another manifestation of a therapeutic and cathartic experience.

The participants provided examples of women losing their hair and even being hospitalized and on the brink of death due to extreme symptoms, and not sharing their situation or its cause with their family members. Thus, receiving no support, which research shows, further exacerbates symptoms. In addition, it was mentioned that a great number of these same individuals whom were secretly suffering did not reach out for the proper medical care and lacked access to resources.

This particular occurrence is important to note because of the specific demographic characteristics of this community. Due to the predominant African-American presence, the interaction of lupus amongst specific ethnicities is important. Not only does lupus occur amongst the composition of the African-American population more frequently, but

It appears that African American women have much more active lupus than other ethnic groups. In fact, the complications from severe kidney disease are greater in the African American community. The reasons for this difference in activity do not seem to depend on socioeconomic factors; however, the most severe manifestations are usually worse in people who wait to have their disease diagnosed or who have poor access to competent physicians. (Lahita & Phillips, 2014, p. 26-27)

Due to this observation and confirmation amongst the participants within Apopka, Florida, it is recommended that further studies regarding knowledge and disseminating information amongst specific ethnic groups is important to future studies.

It is also recommended that future studies should be utilized to cultivate ways in which adult learning strategies can aid individuals in managing their health. It has been

established that education is essential to health. However, it has also been established that there is a gap between research and application. Future studies should also address the effectiveness of the applied research. Further, the notion of the *patient leader* is a relatively new concept. Additional investigation into the support of the *patient leader* and the evolution of self-health management should also be explored.

Also, in terms of community education, it is recommended that the support groups and seminars currently being offered continue to be, and should be, expanded upon.

There is a current need within the community that demands other organizations to take the place where healthcare has either failed or shifted away from. This includes providing information to the public regarding chronic disease, self-health management, creating and sustaining healthy behaviors, how to overcome barriers, and how to discern what information and resources are out there. Furthermore, since it has been proven that self-directed learning readiness characteristics are essential to being an active patient, then there should be program implementation that help participants cultivate these characteristics and expand upon their current capabilities.

The fact that there are specific stringent laws regarding the security of patient information and medical diagnosis, it is difficult to locate individuals that do not self-identify as a lupus patient through organizations such as the Lupus Foundation of America, Inc., and the Lupus Foundation of Florida, needs to be taken into consideration as well. Also, as this study shows, not every individual that attends support group meetings, seminars, and conferences are active patients. Due to the identification and use of a special population, what that means for the passive patient or those who are not

highly self-directed, should be explored. Therefore, future research should investigate the passive patient—specifically, their characteristics and levels of health management.

Prospective studies should also question why the majority of the participants were found to be above average in readiness for self-directed learning. The fact that age, gender, ethnicity, and education level was found to have no significance and the hypothesis was rejected warrants further investigation. The notion that the need for self-directed learning was established as pertinent for survival is important as well. This line of exploration should continue with questioning the nature of this need. Was it a slowly developing disorienting dilemma or sudden and urgent? Research questions revolving around these themes would greatly add to the body of knowledge needed.

Closing Remarks

“It is health that is the real wealth and not pieces of gold and silver”

-Mahatma Gandhi

Roughly sixteen thousand new cases of lupus are diagnosed each year (Lahita & Phillips, 2014). While the investigation into lupus is at an all-time high, it is not enough. Even though organizations such as the Lupus Foundation of America, Inc. and the Lupus Foundation of Florida are creating national awareness campaigns, organizing fundraising walks, and providing social support for persons suffering from the disease, there is still little public notice. It is suggested that lupus is one of the most devastating diseases that the American population remains unaware of.

The varying nature and unknown cause of lupus demands further attention. This need goes beyond biological and medical sciences. The social sciences, and more specifically, education needs to be integrated within this capacity. The findings of this

study are important for researchers, educators, practitioners, as well as patients. It has been established that high levels of self-directed learning readiness is crucial to patients actively managing his/her health. Specifically, being goal-oriented, accepting responsibility, independence, and taking the initiative are characteristics that are found amongst highly self-directed, active lupus patients.

Exploring the relationship between health management and education can only lead to more positive outcomes, behaviors, and health-related results. This understanding, and more specifically the use of adult learning strategies, will alleviate some health barriers and make it more possible for individuals to receive the level of care that they so desperately need. Furthermore, examining the patient in his/her entirety, and not just the clinical nature of lupus, will provide an opportunity for this marginalized group of sufferers to exhibit control, empowerment, and self-efficacy. In turn, catharsis and locus of control can be reached.

APPENDICES

Appendix A. Self-Directed Learning Readiness Scale

SDLRS-A

Name _____ Sex _____ Birthdate _____

Date of Testing _____ Location of Testing _____

LEARNING PREFERENCE ASSESSMENT

Instructions This is a questionnaire designed to gather data on learning preferences and attitudes towards learning. After reading each item, please indicate the degree to which you feel that statement is true of you. Please read each choice carefully and circle the number of the response which best expresses your feeling.

There is no time limit for the questionnaire. Try not to spend too much time on any one item, however. Your first reaction to the question will usually be the most accurate.

RESPONSES

ITEMS:

ITEMS:	Almost never true of me; I hardly ever feel this way.	Not often true of me; I feel this way less than half the time	Sometimes true of me; I feel this way about half the time.	Usually true of me; I feel this way more than half the time.	Almost always true of me; there are very few times when I don't feel this way.
1. I'm looking forward to learning as long as I'm living.	1	2	3	4	5
2. I know what I want to learn.	1	2	3	4	5
3. When I see something that I don't understand, I stay away from it.	1	2	3	4	5
4. If there is something I want to learn, I can figure out a way to learn it.	1	2	3	4	5
5. I love to learn.	1	2	3	4	5
6. It takes me a while to get started on new projects.	1	2	3	4	5
7. In a classroom. I expect the teacher to tell all class members exactly what to do at all times.	1	2	3	4	5
8. I believe that thinking about who you are, where you are, and where you are going should be a major part of every person's education.	1	2	3	4	5
9. I don't work very well on my own.	1	2	3	4	5

	<i>Almost never true of me; I hardly ever feel this way.</i>	<i>Not often true of me; I feel this way less than half the time.</i>	<i>Sometimes true of me; I feel this way about half the time.</i>	<i>Usually true of me; I feel this way more than half the time.</i>	<i>Almost always true of me; there are very few times when I don't feel this way</i>
10. If I discover a need for information that I don't have, I know where to go to get it.	1	2	3	4	5
11. I can learn things on my own better than most people.	1	2	3	4	5
12. Even if I have a great idea, I can't seem to develop a plan for making it work.	1	2	3	4	5
13. In a learning experience, I prefer to take part in deciding what will be learned and how.	1	2	3	4	5
14. Difficult study doesn't bother me if I'm interested in something.	1	2	3	4	5
15. No one but me is truly responsible for what I learn.	1	2	3	4	5
16. I can tell whether I'm learning something well or not.	1	2	3	4	5
17. There are so many things I want to learn that I wish that there were more hours in a day.	1	2	3	4	5
18. If there is something I have decided to learn, I can find time for it, no matter how busy I am.	1	2	3	4	5
19. Understanding what I read is a problem for me.	1	2	3	4	5
20. If I don't learn, it's not my fault.	1	2	3	4	5
21. I know when I need to learn more about something.	1	2	3	4	5
22. If I can understand something well enough to get a good grade on a test, it doesn't bother me if I still have questions about it.	1	2	3	4	5
23. I think libraries are boring places.	1	2	3	4	5
24. The people I admire most are always learning new things.	1	2	3	4	5

	<i>Almost never true of me; I hardly ever feel this way.</i>	<i>Not often true of me; I feel this way less than half the time.</i>	<i>Sometimes true of me; I feel this way about half the time.</i>	<i>Usually true of me; I feel this way more than half the time.</i>	<i>Almost always true of me; there are very few times when I don't feel this way</i>
25. I can think of many different ways to learn about a new topic.	1	2	3	4	5
26. I try to relate what I am learning to my long-term goals.	1	2	3	4	5
27. I am capable of learning for myself almost anything I might need to know.	1	2	3	4	5
28. I really enjoy tracking down the answer to a question.	1	2	3	4	5
29. I don't like dealing with questions where there is not one right answer.	1	2	3	4	5
30. I have a lot of curiosity about things.	1	2	3	4	5
31. I'll be glad when I'm finished learning.	1	2	3	4	5
32. I'm not as interested in learning as some other people seem to be.	1	2	3	4	5
33. I don't have any problem with basic study skills.	1	2	3	4	5
34. I like to try new things, even if I'm not sure how they will turn out.	1	2	3	4	5
35. I don't like it when people who really know what they're doing point out mistakes that I am making.	1	2	3	4	5
36. I'm good at thinking of unusual ways to do things.	1	2	3	4	5
37. I like to think about the future.	1	2	3	4	5
38. I'm better than most people are at trying to find out the things I need to know.	1	2	3	4	5
39. I think of problems as challenges, not stop signs.	1	2	3	4	5
40. I can make myself do what I think I should.	1	2	3	4	5

	<i>Almost never true of me; I hardly ever feel this way.</i>	<i>Not often true of me; I feel this way less than half the time.</i>	<i>Sometimes true of me; I feel this way about half the time.</i>	<i>Usually true of me; I feel this way more than half the time.</i>	<i>Almost always true of me; there are very few times when I don't feel this way.</i>
41. I'm happy with the way I investigate problems.	1	2	3	4	5
42. I become a leader in group learning situations.	1	2	3	4	5
43. I enjoy discussing ideas.	1	2	3	4	5
44. I don't like challenging learning situations.	1	2	3	4	5
45. I have a strong desire to learn new things.	1	2	3	4	5
46. The more I learn, the more exciting the world becomes.	1	2	3	4	5
47. Learning is fun.	1	2	3	4	5
48. It's better to stick with the learning methods that we know will work instead of always trying new ones.	1	2	3	4	5
49. I want to learn more so that I can keep growing as a person.	1	2	3	4	5
50. I am responsible for my learning — no one else is.	1	2	3	4	5
51. Learning how to learn is important to me.	1	2	3	4	5
52. I will never be too old to learn new things.	1	2	3	4	5
53. Constant learning is a bore.	1	2	3	4	5
54. Learning is a tool for life.	1	2	3	4	5
55. I learn several new things on my own each year.	1	2	3	4	5
56. Learning doesn't make any difference in my life.	1	2	3	4	5
57. I am an effective learner in the classroom and on my own.	1	2	3	4	5
58. Learners are leaders.	1	2	3	4	5

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Appendix B. Vanderbilt Pain Management Inventory

<p>Instructions: This questionnaire is designed to assess how often chronic pain patients use active or passive coping strategies when their pain reaches a moderate or greater level of intensity. Please indicate the degree to which you feel that each statement is true of you by checking off the box that best expresses your feeling.</p>				
<p>Vanderbilt Pain Management Inventory (Brown and Nicassio, 1987)</p>				
	Almost never	Sometimes	Frequently	Almost always
1. When you are in pain, do you wish the doctor had prescribed you stronger medicine?				
2. Do you start to think that you're tired and fed up of the pain, that it's too much for you?				
3. Telling others that it hurts a lot.				

4. Praying for it not to hurt so much.				
5. Reducing your social activities (going out less, doing fewer things with people, etc.).				
6. Depending more on others for help with everyday tasks.				
7. Starting to think that you can't do anything to relieve the pain.				
8. Taking medicine to see whether the pain goes away.				
9. Calling a doctor or nurse.				

10. Trying not to feel angry, nor depressed, nor anxious.				
11. Doing physical exercise.				
12. Forgetting the pain.				
13. Busying yourself with lots of things.				
14. Ridding your mind of thoughts that upset you.				
15. Reading (leisurely activities).				
16. Doing something you enjoy.				
17. Trying to distract yourself from the pain.				

Appendix C. IRB Approval



Institutional Review Board
Division of Research
777 Glades Rd.
Boca Raton, FL 33431
Tel: 561.297.0777
fau.edu/research/researchint

Michael Whitehurst, Ed.D., Chair

DATE: March 2, 2015

TO: Valerie Bryan, Kristin Brittain
FROM: Florida Atlantic University Social, Behavioral and Educational Research IRB

IRBNET ID #: 713656-2
PROTOCOL TITLE: [713656-2] Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness

PROJECT TYPE: *New Project*
ACTION: APPROVED

APPROVAL DATE: March 2, 2015
EXPIRATION DATE: March 1, 2016

REVIEW TYPE: Expedited Review
REVIEW CATEGORY: Expedited review category # B7

Thank you for your submission of Response/Follow-Up materials for this research study. The Florida Atlantic University Social, Behavioral and Educational Research IRB has APPROVED your *New Project*. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

- This study is approved for a maximum of 100 subjects.
- It is important that you use the approved, stamped consent documents or procedures included with this letter.
- ****Please note that any revision to previously approved materials or procedures, including modifications to numbers of subjects, must be approved by the IRB before it is initiated.** Please use the amendment form to request IRB approval of a proposed revision.
- All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All regulatory and sponsor reporting requirements should also be followed, if applicable.
- Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.
- Please note that all research records must be retained for a minimum of three years.
- **This approval is valid for one year.** A Continuing Review form will be required prior to the expiration date if this project will continue beyond one year.

If you have any questions or comments about this correspondence, please contact Angela Clear at:

Institutional Review Board
Research Integrity/Division of Research

Florida Atlantic University
Boca Raton, FL 33431
Phone: 561-297-0777
researchintegrity@fau.edu

* Please include your protocol number and title in all correspondence with this office.

**This letter has been electronically signed in accordance with all applicable regulations,
and a copy is retained within our records.**

Appendix D. IRB Protocol

1. Project Summary: This quantitative study investigates the relationship between lupus patients' abilities to cope in relation to their self-directed learning readiness. The purpose of this study is 1) to examine the significance of a patient's active or passive role in terms of his/her health management; 2) to determine if a relationship exists between his/her active and passive scores and his/her self-directed learning readiness, and 3) to identify if his/her view of themselves as a patient (when diagnosed with a chronic disease) impacts his/her own personal health management. The study will examine what, and if, is the relationship between *the Self-Directed Learning Readiness* score and the level of coping abilities measured by the *Vanderbilt Pain Management Inventory* for lupus patients? Also, the study will determine if there are differences within demographic characteristics of age, ethnicity, education level, and gender that affect the relationship between a patient's self-directedness learning readiness and coping abilities? Hypotheses include, that 1) there will be a statistically significant difference in the scores of self-directed learning readiness if a patient is defined by the *Vanderbilt Pain Management Inventory* as being an active versus passive patient. 2) There will be a statistically significant difference within demographic characteristics that moderate a patient's ability to be self-directed and actively cope with his/her disease.

2. Objectives: This research endeavor will be a quantitative analysis of two specific instruments measuring a patient's self-directed learning readiness and his/her ability to manage and/or cope with the illness. In particular, the patient's approaches to learning and personal characteristics will be analyzed and compared to the characteristics associated with the elements of self-directed learning. Furthermore, the researcher will identify self-directed learning elements that are essential for patients actively managing/coping with his/her chronic illness. These characteristics will be identified in hopes of further research and program implementations that will develop leadership abilities in chronically ill patients so they will be able to have a more positive outcome and successfully manage his/her own health.

3. Background & Rationale: Researchers agree that learning is essential to health (Hill, 2011). Adult learning aids individuals through changing physical abilities, medical conditions, lifestyle changes, or social conditions resulting from health related issues (Hill & Ziegahn, 2010) and empowers the individual to become a participant rather than an observer in their own treatment. The notion of being an active patient, an individual who is engaged with health related materials and his/her own self-care is crucial in order to successfully manage one's own health. The majority of research into chronic disease and pain have primarily been based on the physical aspects of the manifestation of pain, This research endeavor will provide insight into the aspects of active and passive coping strategies in conjunction with the relationship between health and education, and will provide knowledge and information to an area that does not receive adequate attention. With the increase of chronic disease, such as Lupus, the complex nature of the American health care system, and push for individuals to become more dynamic and self-sufficient in their health management, research into the field of self-directed learning combined

with health management is essential to successfully navigating one's own health. As the health care system becomes more and more muddled, health-related educational programs are becoming increasingly more imperative. Furthermore, additional research into lupus is vital due to the lack of knowledge and research currently available. As one of the most widespread chronic diseases, lupus needs further attention and serious investigations.

4. Research Plan- Study Design and timeframe: This research endeavor will be a quantitative analysis of two specific instruments measuring a patient's self-directed learning readiness and his/her ability to manage and/or cope with the illness. In particular, the patient's approaches to learning, more specifically self-directed learning, and personal characteristics will be analyzed and compared to the characteristics associated with the elements of self-directed learning. Furthermore, the researcher will identify self-directed learning elements that are essential for patients actively coping with his/her chronic illness. These characteristics will be identified in hopes of further research and program implementations that will develop leadership abilities in chronically ill patients so they will be able to have a more positive outcome and successfully manage his/her own health by actively coping.

The study will include 80-100 participants taking the *Vanderbilt Pain Management Inventory*, an 18-item, self-report measure that assesses how often chronic pain patients use active or passive coping strategies when their pain reaches a moderate or greater level of intensity. The active and passive patients (decided by the *Vanderbilt Pain Management Inventory* tool) will then be compared in levels of self-directed readiness by using the *Self-Directed Learning Readiness Scale* (also known as the Learning Preference Assessment). The researcher will use statistical analysis to determine to what degree the active and passive groups contrast each other. Next, self-directed learning readiness will be measured in both the passive and active groups and the scores will be compared in order to ascertain in what ways specific characteristics of self-directed learning attribute to actively coping with chronic illnesses.

The timeframe for this study is the following: April, 2014: Defend proposal and receive approval to begin research. May- September, 2014: Receive IRB approval and begin preparing instruments for sample. October -November, 2014: Collect Data. November-December, 2014: Analyze data. January, 2015: defend dissertation.

(b) **Research Methods:** This quantitative study will be based upon two instruments, the *Vanderbilt Pain Management Inventory* and the *Self-Directed Learning Readiness Scale*; both tools are self-report and based on a Likert-scale. There is minimal time commitment needed by the participants. The *Vanderbilt Pain Management Inventory* is an 18-item questionnaire that can be completed in less than ten minutes and the *Self-Directed Learning Readiness Scale* is a 58-item questionnaire that can be completed in less than thirty minutes.

(c) **Study Population:** Purposeful sampling will be used in this study. The researcher seeks to access a unique population. 80-100 individuals who are self-reported as being

diagnosed with lupus, a chronic disease, will be selected from the West Palm Beach, Broward, and Miami-Dade counties attending lupus support group meetings.

d) **Recruitment Plan:** The recruitment of participants will take place at the various lupus support groups held throughout the West Palm Beach, Broward, and Miami-Dade counties. The individuals will be contacted directly at the end of meetings. Taking part in the study is a personal choice. The participants of the support group meeting will have an opportunity to refuse to take part in the study since they will be asked after the meeting, and thus, it will not detract from the group's meeting time. The instruments are paper and pencil. Once the meeting is adjourned the participants who stay will be provided with the data collection instruments. The researcher has lupus, and therefore, direct access to the groups through past meetings and interaction. The support groups are open to the general public, anyone affected by lupus. However, only individuals that self-report a positive diagnosis of lupus will be asked to take part in the study. The research will take part once the meeting is over, and therefore, it is not part of the Lupus Foundation's support group official agenda. The researcher is a past member of the group (having Lupus) and has been verbally granted permission to solicit potential participants by the organizational leaders. Since the research study does not affect the group's meeting through time constraint, materials, or topics to be discussed formal permission was deemed as unnecessary from the organization.

(e) **Analysis Plan:** The researcher will gain access to multiple lupus support group meetings to select participants. All subjects in the study will then take the *Vanderbilt Pain Management Inventory* in order to determine which patients are in the active or passive group. Next, the participants will take the *Self-Directed Learning Readiness Scale* (SDLRS) (also known as the Learning Preference Assessment) developed by Guglielmino. The active and passive patients (decided by the *Vanderbilt Pain Management Inventory* tool) will then be compared in levels of self-directedness. The results will be quantified, and the active patients' results will be compared to the passive patients'. The researcher will use statistical analysis to determine to what degree the active and passive groups contrast each other. The scores will be compared in order to ascertain in what ways specific characteristics of self-directed learning attribute to actively coping with chronic illnesses. Lastly, the sample demographic characteristics, age, ethnicity, education level, and gender, that may affect the relationship amongst a patient's self-directedness and coping abilities, will be investigated. In order to properly address this research investigation all data will be analyzed by using the statistical software SPSS.

5. Benefits: This research study will provide knowledge and information to an area that does not receive adequate attention. With the increase of chronic disease, the complex nature of the American health care system, and push for individuals to become more dynamic and self-sufficient in their health management, research into the field of self-directed learning combined with health management is essential to successfully navigating one's own health. Furthermore, additional research into lupus is vital due to the lack of knowledge and research currently available. As one of the most widespread chronic diseases, lupus needs further attention and serious investigations. There is a

sincere lack of research into one of the most prevalent manifestations of a chronic disease. No compensation will be provided to the participants, however, as lupus sufferers they will be assumed to want to add to the study of this disease.

6. Risks: The risks involved with participation in this study are no more than one would experience in regular daily activities. It is unlikely that subjects will experience any harm or discomfort. The participants will not be disclosing any information personally to the investigator regarding his/her chronic pain and health management. The participants will be filling out a self-report questionnaire. The investigator will not ask any participants to disclose any information outside of the instruments used in the study. The presence of the support group should help the participants feel comfortable filling out the information needed. If a participant happens to feel any discomfort he or she is welcome to no longer chose to take part in the study. Subjects may decline to answer any portion of the questionnaire and may conclude the questionnaire at any time and rescind their consent. All information will be kept confidential, as well as any personal information. All research materials will be destroyed two years following the research.

7. Informed Consent Process: The consent forms will be distributed in person after the support group meetings.

8. Informed consent document: A consent form has been drafted based upon the template available on irbnet.org that conforms to the university's requirements. The form has been uploaded to the irbnet.org site for FAU IRB approval.

9. Research Materials, Records, and Privacy: Research materials and records will be transferred digitally onto a computer, saved in an audit trail file kept digitally by the co-principal investigator, and will include the following:

- Participant health status and self-report confirmation of a positive diagnosis of lupus
- Participant demographics: age, ethnicity, education level, and gender
- *Vanderbilt Pain Management Inventory* self-report questionnaire
- *Self-Directed Learning Readiness Scale* self-report questionnaire

This information is needed as a part of the research methods for data collection, analysis, and write-up of findings.

(b) All documents will be digitized and encrypted and stored on an off-line external drive. Only the researcher will have access to the stored data. The documents will be stored for up to two years after the study is completed and then deleted from the principal investigator's external drive and all paper or digital records will be destroyed.

10. Resources:

- (a) No special resources are needed.
- (b) No resources from other sites are needed.

Appendix E. Adult Participant Consent Form

ADULT CONSENT FORM

- 1) **Title of Research Study:** Self-Directed Learning and the Lupus Patient: Using Adult Education Strategies to Actively Cope with Chronic Illness
- 2) **Investigator(s):** Principal Investigator: Dr. Valerie Bryan and Co-Investigator: Kristin Brittain
- 3) **Purpose:** The purpose of this study is 1) to examine the significance of your active or passive role in terms of your health management; 2) to determine if a relationship exists between your active and passive scores related to health management and your self-directed learning readiness score, and 3) to identify if your view of yourself as a patient (when diagnosed with a chronic disease) impacts your own personal health management.
- 4) **Procedures:** This research study consists of two self-report questionnaires: the *Vanderbilt Pain Management Inventory* (VPMI) (Brown & Nicassio, 1987) and the *Self-Directed Learning Readiness Scale* (SDLRS) (Guglielmino, 1977).
You will be asked to complete both questionnaires at the time of signing this consent form. Both tools are self-report and are based on a Likert-scale. There is minimal time commitment needed, approximately 20-30 minutes to complete both questionnaires, for this effort on your part. The *Vanderbilt Pain Management Inventory* is an 18-item questionnaire that can be completed in less than ten minutes and the *Self-Directed Learning Readiness Scale* is a 58-item questionnaire that can be completed in less than thirty minutes.
- 5) **Risks:** The risks involved with participation in this study are no more than one would experience in regular daily activities. You may decline to answer any portion of the questionnaire and may conclude the questionnaire at any time and remove your consent to participate if you begin to feel any discomfort disclosing information regarding your health and chronic pain management. All information will be kept confidential, as well as any personal information.
- 6) **Benefits:** We do not know if you will receive any direct benefits by taking part in this study. However, this research will contribute to a greater understanding of specific coping strategies utilized by lupus patients and the relationship between health and education for lupus patients.
- 7) **Data Collection & Storage:** Any information collected about you will be kept confidential and secure and only the people working with the study will see your data, unless required by law. The data will be kept for two years in a locked cabinet [or password-protected computer or password protected USBs] in the investigator's office. After two years, paper copies will be destroyed by shredding and electronic data will be deleted or destroyed. We may publish what we learn from this study. If we do, we will not let anyone know your name/identity unless you give us permission.
- 8) **Contact Information:**

- If you have questions about the study, you should call or email the principal investigator(s), Dr. Valerie C. Bryan, 954-592-3224, or Kristin Brittain at (954) 234-5207 or email at kbrittai@fau.edu.
- If you have questions or concerns about your rights as a research participant, contact the Florida Atlantic University Division of Research at (561) 297-0777 or send an email to fau.research@fau.edu.

9) Consent Statement:

*I have read or had read to me the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. I have received a copy of this consent form.

Yes _____ No _____ I consent to being a participant in this research.

Yes _____ No _____ I consent to having my results published as part of the analysis without my name attached.

Signature of Participant: _____ Date: _____

Printed Name of Participant: First Name _____ Last Name _____

Signature of Co-Investigator: _____ Date: _____



Approved on:	3/2/2015
Expires on:	3/1/2016

Institutional Review Board

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