ABSTRACT

WILKINS, JEFFERY L. The Role of Self-Care Management Support Groups for Individuals with Sickle Cell Disease. (Under the direction of Dr. Kwesi C. Brookins).

Chronic illness is a significant public health concern in the United States. The CDC estimates that nearly 70% of annual US deaths involve chronic medical conditions. Chronic diseases are associated with activity limitation, premature mortality, reduced quality of life and a variety of adverse physical and mental health outcomes. The present study examined the chronic medical condition of sickle cell disease, a heritable blood disorder that, in addition to the above, produces excruciating pain and fatigue. Individuals living with chronic medical conditions use face-to-face and online support groups to exchange social support, information, and self-care management techniques to alleviate some of these negative consequences.

In an overall sample of 87 participants, this study examined how individuals with sickle cell disease use online and face-to-face support groups to enhance self-care management resources such as social support, self-efficacy, and self-care ability and compared the effectiveness of support group type in coping with the disease. This study used a non-experimental, nonequivalent group design to assess participants’ membership and involvement in support groups and the impact this participation had on self-care management resources. Correlational analyses examined the strength of the relationship between self-care management resources (SCMR), sense of community, sense of virtual community, and quality of life scores. An Independent-samples T-test assessed the relationship between support group participation and SCMR. An ANCOVA was used to examine the differences in SCMR scores between face-to-face and online support groups and online only support groups with demographic variables and intensity of participation as covariates. The findings revealed that participants in support
groups did not have higher SCMR scores than those who were not in support groups. Also, support group type (i.e., traditional or virtual) did not significantly affect SCMR.

Moreover, data analysis revealed a significant positive relationship between SCMR and sense of virtual community scores and a significant negative correlation between SCMR and quality of life scores, whereby participants who reported higher SCMR had fewer days of poor physical and mental health. The implications of this research have far-reaching applications in improving the quality of online support groups. Study data suggests that health care professionals can add online platform interactions to their practices to offer better self-care management technique programming that promotes mental and physical health outcomes. Moreover, this investigation identified numerous opportunities for future research that can illuminate best practices for support group facilitators.
The Role of Self-Care Management Support Groups for Individuals with Sickle Cell Disease

by
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DEDICATION

I would like to dedicate this dissertation to every individual living with sickle cell disease. It takes strength of mind, body, spirit, and character to fight this debilitating illness. I sincerely hope that those who are impacted by SCD are inspired by this momentous accomplishment and are encouraged to follow their dreams and passions.

I also dedicate this dissertation to my parents, Thomas and Betty Wilkins and my siblings Tasha and Daniel whose unwavering love and support made this possible. The knowledge that you were with me pulled me through the most difficult moments of my life. To my wife, Emily, thank you for your love and support. Your steadfast love kept me going even when I thought I could go no further.
Jeffrey L. Wilkins was born in Charlotte, NC to Thomas and Betty Wilkins. He attended Phillip O. Berry Academy of Technology. He obtained a Bachelors in Psychology from North Carolina State University, a Masters in General and Experimental Psychology from North Carolina Central University. With the completion of this dissertation, he has earned a Doctorate of Philosophy in Applied Social and Community Psychology from North Carolinas State University. Jeffrey is a instructor of experimental psychology and statistics at North Carolina Central University. He enjoys reading science fiction, spending time with family and friends, trying new cuisines with my wife, gardening, cooking, playing golf, and fishing.
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# TABLE OF CONTENTS

LIST OF TABLES .................................................................................................................. vi
LIST OF FIGURES ................................................................................................................. vii

CHAPTER 1: INTRODUCTION ............................................................................................... 1
Sickle Cell Disease .................................................................................................................. 2
Theory of Self-care Management for Sickle Cell Disease ..................................................... 3
The Role of Social Support in Managing SCD ...................................................................... 5

CHAPTER 2: LITERATURE REVIEW ..................................................................................... 7
Support Groups and Self-Care Management Resources ...................................................... 7
Virtual Support Groups ........................................................................................................ 8
Face-to-face Support Groups ............................................................................................... 12
Social Support, Self-efficacy and Quality of Life ................................................................ 15
Purpose of the study ........................................................................................................... 19

CHAPTER 3: METHODOLOGY ............................................................................................. 21
Participants .......................................................................................................................... 21
Procedures .......................................................................................................................... 21
Measures ............................................................................................................................. 22
Statistical Analyses ............................................................................................................. 25
Sample Size ......................................................................................................................... 25

CHAPTER 4: RESULTS ......................................................................................................... 27
Descriptive Statistics ........................................................................................................... 27
Demographic Statistics ....................................................................................................... 27
Hypothesis Testing .............................................................................................................. 27
Completers vs Non-completers .......................................................................................... 30

CHAPTER 5: DISCUSSION ................................................................................................... 33
Limitations ............................................................................................................................ 38
Future Research .................................................................................................................. 40
Practical Implications ......................................................................................................... 41
Conclusion ........................................................................................................................... 41

REFERENCES ....................................................................................................................... 43

TABLES AND FIGURES ...................................................................................................... 50

APPENDICES ...................................................................................................................... 56
Appendix A ........................................................................................................................... 57
Appendix B ............................................................................................................................ 60
Appendix C ............................................................................................................................ 61
LIST OF TABLES

Table 1  Self-care management resource means by support group ........................................ 50
Table 2  Means and reliability for dependent variables .............................................................. 50
Table 3  Demographic variables by support group type ............................................................... 51
Table 4  Pearson correlation between self-care ability and sense of community scores .......... 51
Table 5  Correlation between social support and sense of community scores ......................... 52
Table 6  Correlation between self-efficacy and sense of community scores .............................. 52
Table 7  Correlation between self-care management resources and sense of virtual community .......................................................... 52
Table 8  Correlation between self-care management resources and quality of life ............... 53
Table 9  ANCOVA between self-care ability and support group participation ......................... 53
Table 10 ANCOVA between social support and support group participation .......................... 53
Table 11 ANCOVA between self-efficacy and support group participation ............................. 54
LIST OF FIGURES

Figure 1  Visual relationship between vulnerability factors, support groups, SCMR, and QoL .......................................................... 55

Figure 2  Computational model of the relationship between support groups, self-care management resources and quality of life .............................................. 55
CHAPTER 1: INTRODUCTION

Chronic illness is a major public health concern in the United States. The CDC (2015) estimates that nearly 70% of annual US deaths involve chronic medical conditions. Furthermore, chronic medical conditions result in activity limitations for nearly 10% of US adults (CDC, 2015; Sansom-Daly et al., 2012). Examples of common chronic illnesses are rheumatoid arthritis, diabetes, heart disease, sickle cell disease, and fibromyalgia. Past research indicates that chronic medical conditions are associated with a variety of poor psychological outcomes such as reduced health-related quality of life, poor quality of life, self-efficacy, emotional distress, a decrease in perceived control, and physiological symptoms (Wikman, Wardle, & Steptoe, 2011).

Chronic illness’ impact on health-related quality of life is of particular interest. Quality of life has numerous definitions; however, most include some measurement of domains such as one’s global life satisfaction, education, family and personal safety, sufficient housing, general physical and mental health, the pursuit of leisure, and social behaviors (Mann-Jiles & Morris, 2009). These domains reflect general measures of quality of life. However, general health-related assessments of the quality of life exist as well as measures for specific diseases such as Asthma and COPD (Mann-Jiles & Morris, 2009; Hesselink et al., 2004).

Current literature suggests that support groups, whether face-to-face, or virtual/online, may provide individuals suffering from chronic illness(es) with opportunities to interact socially and thus gain social support (Cantrell, 2015). Furthermore, disease-specific symptoms and health need factors influence psychological well-being and physical health status. These factors and their physical and mental health consequences can be mitigated using self-care management resources such as self-efficacy, social support, and self-care ability (Jenerette and Murdaugh, 2008). Past research has examined how virtual communities (VCs) are used by patients with
HIV/AIDS and ALS to exchange information and social support. However, little or no research has examined this phenomenon among individuals with sickle cell disease (Loane & D’Alessandro, 2013; Mo and Coulson, 2008; Willis, 2014).

**Sickle Cell Disease**

Sickle cell disease (SCD) is a genetically inherited disorder whereby various abnormal types of hemoglobin (Hb S) specifically, Hb-SS, Hb-Beta- SC, and Hb- Thalassemia present within red blood cells (Maakaron & Taher, 2015; Edwards et al., 2005). Hemoglobin (Hb) SS, SC, and Beta Thalassemia are the names given to specific anomalies or mutations in hemoglobin that cause sickle cell; similar to the nomenclature given to distinguish type 1 or 2 diabetes (Edwards et al., 2005). The hemoglobin mutations that cause sickle cell disease are due to an adaptation to reduce infection from malaria carried by mosquitoes. Therefore, sickle cell trait and sickle cell disease are found in population with higher exposure to malaria, specifically Africa, South America, and India. SCD occurs in approximately 1 in 365 African Americans, while sickle cell trait has a prevalence rate of 1 in 13 African Americans born in the US (CDC, 2019). Sickle cell disease has several symptoms including intense pain crises, fatigue, and increased risk to illness. These symptoms are psychosocially disruptive (Edwards et al., 2005; Gold, Treadwell, Weissman, & Vichinsky, 2011). Physiologically, pain in SCD is caused by vasoocclusion or the restriction of blood flow due to the sickling of blood cells, which can occur in any musculoskeletal part of the body.(Edwards et al., 2005; Telfair & Gardner, 1999). The “sickling” of blood cells is caused by the mutated hemoglobin in blood cells becoming rod-like when deoxygenated, which deforms blood cells into crescent-shaped cells that clump together obstructing blood flow in blood vessels (Edwards et al., 2005). Although its symptoms are well-known, not enough is known about how SCD relates to psychological outcomes, such as quality
of life and social support.

The genetically inheritable characteristics of SCD mean that patients with the illness are born with it and live their entire lives coping with its effects. This distinguishes SCD from various other chronic medical conditions explored in other studies. Numerous chronic illnesses are acquired and develop later in life, particularly in adulthood. Individuals coping with other chronic diseases such as rheumatoid arthritis and amyotrophic lateral sclerosis (ALS) are, on average, much older and have likely lived relatively healthy childhoods, adolescence, and a portion of adulthood. Adults living with SCD, however, have had to learn to manage the symptoms and complications of the disorder throughout childhood, adolescence, and adulthood, negotiating the physical and psychosocial complications of each developmental stage and the disease itself. The primary theory informing this research is the theory of self-care management for sickle cell disease.

Theory of Self-care Management for Sickle Cell Disease

Self-care management refers to the daily tasks that individuals with chronic illness conduct to manage their health (AHRQ, 2015). Self-care management strategies are important because maintaining good health practices at home helps reduce the need to utilize health care services (Jenerette & Murdaugh, 2008). The theory of self-care management for sickle cell disease (SCMMS) asserts that within SCD vulnerability factors such as sociodemographic (e.g., gender, age, etc.) and health (e.g., health care utilization, the number of sickle cell crises experienced per year) have a negative effect on health status and quality of life (Jenerette & Murdaugh, 2008). The theory also asserts that self-care management resources positively mediate the relationship between vulnerability factors, health status, and quality of life. Self-care
management resources refer to positive psychological and behavioral factors such as self-care ability, social support, self-efficacy, self-care actions, coping behaviors, assertiveness, and communication skills (Jenerette & Murdaugh, 2008).

Vulnerability factors such as age, gender, socioeconomic status (SES), and health needs factors, like sickle cell pain crises and health care utilization (i.e., hospitalization, doctor visits), are connected in a myriad of ways. For example, on average younger patients experience more frequent pain crises. Furthermore, lower SES individuals who have frequent healthcare utilization report lower quality of life and overall health status (Jenerette & Murdaugh, 2008).

The theory of self-care management proposes that the deleterious effects of vulnerability factors on health status and quality of life can be mediated for the individual by deploying self-care management resources such as social support, self-efficacy, and self-care ability. These resources and strategies are a critical tool in improving health status and quality of life. Virtual communities and face-to-face support groups can provide individuals with SCD an opportunity to gain and use the specific self-care management resources of social support, self-efficacy, and self-care ability, thus improving health status and quality of life.

Sickle cell disease’s life-long nature produces conditions in which the development and maintenance of protective psychosocial factors, such as social support and self-care techniques, are critical for managing a health quality of life (Silva et al., 2011). The theory of self-care management for sickle cell disease (SCMSCD) suggests that the specific characteristics and vulnerability factors of SCD, namely frequent pain crises, fatigue, healthcare utilization, and demographics variables, negatively impact the health and quality of life of sufferers (Jenerette & Murdaugh, 2008). These negative effects can be mediated by self-care management resources like social support, self-care actions and ability, self-efficacy, and other coping behaviors to
improve quality of life and general health status (Jenerette & Murdaugh, 2008). Traditional and online support groups may provide individuals living with sickle cell disease the opportunity to utilize these self-care management resources and offer an effective tool with which to combat the negative consequences of the disorder.

The Role of Social Support in Managing SCD

Individuals with chronic illnesses like sickle cell disease often seek social support via face-to-face meetings with others who have the same medical condition (Winzelberg et al., 2003). These face-to-face support groups provide members with opportunities to share frustrations, accomplishments, and gain new self-care management techniques. The advent of technology and the accessibility of the internet permits people with chronic illnesses to connect across time and space to create online support groups. These online support groups allow individuals with chronic illnesses to share experiences, exchange support, gain self-management strategies, and form a sense of community. Communities that form using computer networking technology (i.e., internet) are often classified as online or virtual communities (Blanchard, 2008).

Past research has examined how individuals with a variety of chronic medical conditions use support groups to exchange social support and self-care techniques (Willis, 2014; Stinson et al., 2010; Cantrell, 2015). This literature is replete with studies examining how individuals with rheumatoid arthritis, ALS, Alzheimer’s Disease, AIDS, and a plethora of cancers, gain social support and manage their medical conditions using support groups. There is a gap in the literature exploring how individuals with sickle cell disease manage their disease through support groups. This is true for traditional face-to-face support groups as well as groups that take advantage of new computer-mediated (i.e., online/virtual) communication technologies.
In summary, the particular characteristics of SCD make it critically important to better understand the best practices for extending support resources to individuals with the disorder, with the goal of improving their mental and physical well-being. Accordingly, this study was designed to understand how individuals with sickle cell disease use support groups, whether virtual or face-to-face, to enhance self-care management resources such as social support, self-efficacy, and self-care ability, as postulated by the theory of self-care management (See Figure 1). By generating additional empirical evidence on support, resources will help healthcare providers, and mental health professionals understand how online and face-to-face support groups can be used to encourage self-care management techniques and ultimately improve the lives of their patients.
CHAPTER 2: LITERATURE REVIEW

Minimal research is available assessing the use of traditional and online support groups to exchange social support and gain self-care management resources among individuals living with sickle cell disease. However, numerous studies exist that have assessed the relation between social support, self-efficacy, self-care behaviors and ability, health-related quality of life, and various support groups for other chronic medical conditions.

Chronic medical conditions require patients to complete a variety of self-care tasks in order to manage and cope with the symptoms and consequences of their disorders. Healthcare professionals provide patients with information and counseling on techniques to manage their medical conditions. However, this guidance often lacks the interpersonal and psychosocial engagement that helps individuals cope with illness (Cohen, Gottlieb, & Underwood, 2000). Support groups provide additional resources and opportunities for individuals with chronic medical conditions to gain social support and learn other self-care management strategies from other patients including psychosocial, and behavioral resources that cannot be acquired from healthcare providers.

Support Groups and Self-Care Management Resources

Support groups are used by a variety of populations with have mental illnesses, physical disabilities, and chronic illnesses to discuss their challenges, successes, and self-care techniques. Support groups provide their members with an opportunity to interact with others that share the same or a similar chronic illness. Support groups are classified based upon the methods participants use to communicate with one another. Typically, participants meet within face-to-face (F2F) groups in a variety of settings (i.e., hospitals, doctor’s offices, conference rooms, etc.)
to discuss disease-related and psychosocial sequelae. F2F support groups provide their members with opportunities to interact in person and discuss self-care management strategies they can use to deal with their chronic illnesses. Increasingly, computer-mediated communication systems using the internet have afforded patients the opportunity to use social media, newsgroups, and online message boards (or forums) to construct virtual communities as support groups (Blanchard and Markus, 2008; Josefsson, 2005).

**Virtual Support Groups**

Virtual or online support groups sometimes called virtual communities (VCs) offer their members the opportunity to provide/exchange social support, create identification, and produce trust with one another (Blanchard, 2008). While online, members of VCs interact asynchronously or synchronously but are separated by both space/distance and time. Examples of VCs include Facebook, Twitter, and online message boards like Reddit. Virtual communities provide individuals with chronic medical conditions many of the same benefits F2F groups do, especially social support and improvements in quality of life and health-related quality of life (HRQoL) (Winzelberg et al., 2003). Members of virtual communities with sickle cell disease can discuss disease-specific symptoms, psychosocial complications, and share helpful self-care management strategies (Jenerette & Murdaugh, 2008). These strategies can improve both mental and physical health (Blanchard, 2008; Blanchard & Markus, 2004). Furthermore, virtual health communities provide psychological benefits like social support and assist members in health promotion and self-care management strategies. Moreover, patients who use VC may feel more inclined, to be honest or reveal elements of their true social identity online because of the anonymity provided by online communication (Cantrell, 2015). Cantrell (2015) noted that online support groups afford a measure of comfort for its members and thus allows them to have
discussions that they may be able to in a traditional or in-person setting.

Past research has explored the use of virtual support groups or virtual communities to improve health, well-being, and provide social support for individuals with chronic illnesses. Loane & D’Alessandro (2013) found that among individuals with arterial lateral sclerosis (ALS) online health communities allowed members to exchange social support, particularly emotional and informational support. Moreover, among individuals living with HIV/AIDS, virtual health communities permitted members to exchange emotional and informational support, as well as tangible, esteem, and social network support (Mo and Coulson, 2008). Online support groups have also been utilized by individuals with rheumatoid arthritis (RA) (Willis, 2014). Willis (2014) mentioned the exchange of social support, and noted nearly 70 percent of posts contained content relevant to self-care management behavior.

Virtual support groups and the online communities they create come in a variety of modalities that allow participants to exchange social support and self-care management resources (SCMR). Health vlogs (or health video logs; VLOGs) are online videos hosted on medical websites, topical sites, and YouTube that allow patients with chronic illnesses to document their experiences and share information and self-care management strategies with online audiences. Vlogs often become an online support group for people with chronic illnesses. Huh, et al. (2014) examined the use of health vlogs for people with cancer, diabetes, and HIV. Using a qualitative methodology, the researchers analyzed videos posted by vloggers, as well as the comments to those videos, and coded for content that reflected social support content, the reasons for vlogging, and the reasons for reading the vlogs. The researchers found that vlogs for both the vlogger and the viewers helped to educate, encourage, and inspire one another. Furthermore, vlogging served to form social bonds among users across medical conditions and engendered
social support (Huh, Liu, Neogi, Inkpen, Pratt, 2014). Health vlogs were not established to be support groups. This research, however, suggests that they can promote community and the exchange of various types of social support.

Additional research has further examined the efficacy of internet-based self-management support group programs on improving self-efficacy, health-related quality of life, social support, stress-reducing pain, and emotional distress among adolescents with rheumatoid arthritis (RA). Stinson and colleagues (2010) designed and implemented a 12-week internet-based self-management and telephone program for adolescents with RA. The experimenters found that participants in the experimental self-management program reported significantly lower average pain ratings and knowledge of their medical conditions than those in the control (informational/educational website) group. However, there were no statistically significant differences in self-efficacy, stress, and HRQoL between the experimental and control groups (Stinson et al., 2010).

The results of Stinson's and colleagues' study suggested that individual online programs that seek to improve self-management techniques show efficacy in enhancing disease-specific knowledge and skills and reducing pain for adolescents with arthritis. However, this program lacked empirical evidence indicating its positive impact on participants’ self-efficacy, health-related quality of life (HRQoL), or ability to cope with stress. Their results suggested that interventions directed at improving self-care management strategies and resources likely need a social component in which participants interact with one another to exchange support, not just educational/informational content. Support groups offer an environment in which individuals living with chronic illness can exchange support, discuss disease-specific and psychosocial self-care techniques, encourage positive behavioral change, and gain self-efficacy. Moreover, the
failure to reveal significant differences in HRQoL and self-efficacy may have been due to a low sample size (n=22).

Online support groups for chronic medical conditions provide members with opportunities to exchange social support and disease-specific self-care management strategies. A number of research studies conducted by Huh et al., (2014), Stinson and colleagues (2010), and Willis (2014) suggested that support groups hosted in virtual spaces can be effective in providing participants with social support, self-efficacy, and self-care management strategies, and improve quality of life. A critical assessment of these studies allows us to draw conclusions about best practices and characteristics of online support groups as an intervention for improving quality of life, enhancing self-care management resources, and providing social support. For instance, the opportunity for group members to socialize with one another appears to be critically important, particularly online, where anonymity is assumed and available (Stinson et al., 2010; Cantrell, 2015). Furthermore, the structure and characteristics of the website or forum in which the online support group is hosted is also an important factor affecting how participants interact with one another online. Chen and Lin (2008) indicated that there are certain characteristics hosting sites must have in order to foster a sense of virtual community and thus enhance the ease and quality of online interactions. Specifically, Chen and Lin (2008) noted that system quality (SQ) is an important factor in the creation and maintenance of online spaces like social media and other social networking sites that often host online support groups. System quality refers to the usability features of the online platform that allows members to comment on one another’s posts and the overall ease of use of the interface that participants use to communicate and exchange support. These features helped create a sense of virtual community that allowed individuals with chronic medical conditions interact more effectively in support groups (Chen and Lin, 2008).
Although several studies suggested that there are benefits to online support groups for individuals with chronic medical conditions, other studies noted that it is not always effective. Eysenbach and colleagues (2004) conducted a literature search of computer-based peer-to-peer communities and online support groups. The researchers reviewed 45 published articles that explored 38 studies covering a variety of methodologies that assessed the effectiveness of support groups. Research designs included randomized trials, meta-analyses, non-random trials, and pre-posttests. Most studies (31) utilized a researcher sponsored support group as an intervention and included psychoeducational programs or individual communication with a healthcare professional (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). The primary outcome variable for these studies was depression and/or social support measures, of which the researchers concluded there were no significant effects (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). It should be noted that the use of the experimenter created support groups as an intervention may have hindered the development of a sense of community. Furthermore, the involvement of healthcare professionals in the structured support group community may reduce the organic development of communities and sense of community and thus detract from the development of a sense of community and hinder the effective exchange of social support.

In summary, the extant research suggests that online health communities for people with chronic illnesses likely provide measurable benefits for their members through opportunities to interact, exchange information, social support, and self-care management strategies.

**Face-to-face Support Groups**

Support groups have traditionally been organized and hosted in face-to-face and physical spaces. Regardless of the method, whether face-to-face or online, support groups bring
individuals with chronic illnesses together to discuss their conditions in a safe and open environment. The benefits of support groups for patients with chronic illnesses has been a topic of research for decades. Clark and colleagues (1992) explored how participation in a support group for teens with cancer and hematological diseases (including SCD) impacted social skills, support, and quality. The experimenters formed an F2F support group for adolescents with cancer and blood disorders (including SCD) to interact with one another over a period of two years. The researchers found that participation in a support group resulted in 75% of patients agreeing or strongly agreeing that the support group helped them cope with having a chronic illness. Participants also agreed or strongly agreed that the support group lessened the burden of being hospitalized and reduced loneliness, thus improving their QoL. Furthermore, participants of the support group indicated that it helped strengthen their understanding of themselves and helped cope with social problems related to their illness (Clark et al., 1992).

The findings of Clark and colleagues are further corroborated by Kennedy and colleagues (2013), who observed how a ley-led F2F self-care support group program affected participants’ self-efficacy, quality of life, and health status. The experimenters utilized a pre-posttest, between-subjects experimental design in which 629 participants with a variety of long-term chronic conditions were recruited from Strategic Health Authorities in England, UK. Participants were reported to have chronic conditions of the musculoskeletal, endocrine, circulatory, respiratory, mental health, and neurological systems. Participants were randomly assigned to a treatment or control (waitlist) conditions. The treatment condition intervention was a program developed in the United States called the chronic disease self-management programme (CDSMP) that was adapted for patients in England. The CDSMP is a layperson led program designed to help patients develop and improve self-care abilities. This program is a 2.5-hour
course that groups of 8-12 patients attended weekly for six sessions, of which full completion was defined as attending four or more sessions. The CDSMP is a uniform program that utilizes trained lay volunteers as facilitators that lead participants in sessions teaching diet, exercise, relaxation techniques, pain management, medication adherence, doctor-patient communication skills, and goal-setting skills. Participants actively engage with one another in sessions to discuss self-care strategies, goal setting successes and challenges, and social support. Social learning theory was a guiding principle of CDSMP (Kennedy et al., 2013).

Prior to initiation of the support group, participants in both conditions were administered a pretest assessing quality of life (EuroQoL), demographic characteristics (i.e., gender, SES, marital status, age, employment status, etc.), health status, self-efficacy, and health care utilization. Data were also collected at six and twelve-month follow-ups. The researchers hypothesized that participants in the treatment group would experience a positive change in self-efficacy scores, self-care behavior, and health status. It was further hypothesized that changes in self-efficacy scores would increase overall health status and therefore result in reduced healthcare utilization. The researchers analyzed data using an ANCOVA with demographic variables serving as covariates. Data analysis revealed that participants in the intervention scored significantly higher on self-efficacy scores, energy (health status subdomain) scores, psychological well-being, exercise, partnership with providers/clinicians, relaxation scores, and health-related quality of life. Moreover, control group participants reported greater health distress scores (Kennedy et al., 2013).

Kennedy and colleagues (2013) investigated a self-care support group intervention program among adults in the U.K with a broad range of chronic long-term medical conditions. The experimenters’ evaluation of the program indicated that an F2F lay-led self-care support
program may increase the self-efficacy, health status (specifically energy levels), and health-related quality of life of individuals living with chronic medical conditions. This study suggested that not only can support groups improve QoL and self-efficacy of chronic illness sufferers but that a targeted program facilitated by laypersons can be effective in doing so. It is important to note that this program was an intentionally organized and administered support group intervention rather than a patient created and facilitated support group. The structured and empirically based organization of this program differed from support groups that are organized and facilitated by patients. Thus, its effectiveness may be due to its structured and prescribed organization which contrasts with the more organically organized, patient-led support groups.

One of the critically important benefits of support groups is their ability to offer participants an opportunity to learn and exchange self-care management strategies and techniques, thus enhancing patients’ self-care management resources (Jenerette & Murdaugh, 2008). Support groups, whether online or F2F, provide individuals with a chronic illness such as sickle cell disease with a safe space to discuss the psychosocial and physical consequences of having a medical condition. The opportunity to provide and receive social support and other self-care management resources can improve overall psychological well-being and quality of life.

**Social Support, Self-efficacy and Quality of Life**

Social support is a critical component in coping with chronic illness and maintaining one’s quality of life (Mo and Coulson, 2008; Loane & D’Alessandro, 2013). There are several common types of social support: emotional, informational, tangible, esteem, and social network support. Past research has examined the psychological determinants of quality of life finding that social support is correlated with and predictive of quality of life in several chronic illnesses such
as schizophrenia, obesity, and congenital heart disease (Silva et al., 2011; Bechdolf et al., 2003).

Self-care management resources (SCMR) allow individuals with sickle cell disease and other chronic illnesses to reduce the deleterious psychosocial and physical consequences of their medical conditions and improve quality of life. In addition to social support and self-care behaviors, self-efficacy is an important SCMR. Self-efficacy is defined as “… a person’s beliefs about how capable he or she is in performing the behaviors needed to bring about the desired outcome” (Bonsaksen, Lerdal, and Fagermoen, 2012, p. 333). Self-efficacy has also been described as a person’s confidence in their ability to perform an action or set of actions (Fan and Lv, 2016). In his theory of social learning, Bandura (1982) suggested that self-efficacy is a person’s belief in their ability gain the motivation to build resources and complete actions/behaviors needed to influence the events that affect their lives. This belief and motivation helps people plan and complete the actions needed to change their lives (Namkoong, 2010). Self-efficacy is associated with a variety of psychosocial and physical health factors.

Bonsaksen and colleagues (2012) explored these factors with a sample of participants living with morbid obesity and chronic obstructive pulmonary disease (COPD). They assessed self-efficacy by using the general perceived self-efficacy scale (GSE), a 10-item questionnaire that is scored on a four-point Likert type scale. The GSE has high reliability with an alpha of .92 (Bonsaksen, Lerdal, and Fagermoen, 2012). Data were analyzed using bivariate correlations and hierarchical linear regression. The analyses indicated that higher levels of social support and physical activity were associated with higher levels of self-efficacy. Regression modeling suggests that social support explained 4.1% of the variance in self-efficacy and emotional control explained 5.3% of the variance in self-efficacy scores. The investigation of self-efficacy
by Bonsaksen and colleagues (2012) suggested that social support strongly relates to self-efficacy. Past research has further explored the relationship between self-efficacy and quality of life.

Fan and Lv (2016) studied self-efficacy and its psychosocial factors among patients with chronic heart failure (CHF). The researchers sampled 159 individuals with CHF recruited from cardiovascular clinics at two hospitals in China. Participants completed demographic questionnaires, and self-efficacy was measured using the self-efficacy for managing chronic Disease (SECD6) short form ($\alpha=0.90$). The SECD scores self-efficacy based upon the average of a scale of 1 to 10 (high self-efficacy) for each item. The researchers also measured general self-efficacy using the general self-efficacy scale which is a non-specific measure of self-efficacy (Fan and Lv, 2016). Data were also collected to measure anxiety, depression, and perceived social support. Data analysis included t-test, one-way ANOVA, Pearson correlation, and stepwise linear regression. Scores for SECD that were less than seven were considered low or inadequate self-efficacy. Correlation analysis indicated that general self-efficacy and perceived social support scores were positively correlated with SECD scores.

Moreover, SECD scores were negatively related to anxiety and depression scores. Regression analysis indicates that general self-efficacy and social support scores were predictive of self-efficacy for managing chronic disease (SECD) scores, adding depression scores to the model and these three variables accounted for 29% of the variance in SECD scores. Fan and Lv’s (2016) study suggested that within individuals living with chronic disease, specifically chronic heart failure in China, self-efficacy in managing a chronic illness was consistently related to social support and general self-efficacy. This study corroborates the findings of Bonsaksen, Lerdal, and Fagermoen (2012).
Additional research studies have further investigated the role of self-efficacy in chronic illness for self-management/self-care management strategies. A review of practice and intervention implications of self-efficacy in chronic illness conducted by Marks, Allegrante, and Lorig (2005) noted that self-efficacy is associated with and impacts a number of health-related and psychosocial factors. Self-efficacy is associated with healthy behavior such as medication adherence, physical activity, healthy diet, life expectancy, and overall physical functioning. Self-efficacy is important for and influences motivation and attitudes toward health-promoting behaviors (Marks, Allegrante, and Lorig, 2005). Furthermore, psychosocial factors such as social support and quality of life are associated with self-efficacy (Marks, Allegrante, and Lorig, 2005). The authors concluded that interventions aimed at improving health and quality of life among individuals living with chronic illness and should consider self-efficacy as a factor in modifying health behavior and improving self-care management techniques.

Past research has also explored the impact of online health support groups on self-efficacy. Namkoong and colleagues (2010) assessed the association between health self-efficacy, treatment information, and emotional well-being in a computer-mediated support group among breast cancer patients. The researchers studied a sample of 177 breast cancer patients who interacted in an online health program discussion forum over a period of 4 months. Hierarchical regression analysis suggested that in the patient exchanging of information (treatment information), there was a positive impact on emotional well-being for participants with higher health self-efficacy. However, the researchers also found that there was a negative influence on the emotional well-being of participants with lower self-efficacy (Namkoong, 2010).

Self-efficacy is an important construct in improving health and quality of life among individuals living with chronic disease. Given the chronic nature of sickle cell disease, self-
efficacy is also an important aspect of self-care management resources that can be used to improve the health and lives of sufferers of SCD. Examining how self-efficacy improves self-care behavior and acts as a self-care management resource further advances our understanding of how SCMR improves the lives of individuals living with SCD. Moreover, investigating the use of support groups to gain social support, self-efficacy, and self-care management resources allows us to understand better how support groups, whether virtual or traditional, enhance the quality of life among individuals with sickle cell disease.

**Purpose of the study**

The current study examines how virtual communities are used to improve the psychological well-being of individuals living with sickle cell disease. This study sought to understand how individuals with sickle cell disease use support groups, whether virtual communities or traditional face-to-face support groups, to enhance self-care management resources such as social support, self-efficacy, and self-care ability to improve quality of life. This study also sought to compare the efficacy of virtual versus face-to-face support groups to help patients cope with the disease by strengthening self-care management resources such as social support, self-care ability, and self-efficacy. This research is guided by the theory of self-care management for sickle cell disease.

**Research Questions**

A). What is the relationship between participation in support groups and self-care management resources?

H1) Support group participants will report higher mean SCMR scores (self-care ability, social support, and self-efficacy) than those in no support group.
B.) What is the relationship between sense of community and each of the self-care management resources (self-care ability, social support, and self-efficacy)?

H1.) Sense of community scores will be positively correlated with each self-care management resource scores (self-care ability, social support, self-efficacy)

C.) What is the relationship between self-care management resources and quality of life for all participants with SCD?

H1.) Self-care management resources scores will be negatively correlated with poor quality of life scores.

D.) Are there differences in self-care management resources between participants in F2F and online groups and online only support groups when controlling for intensity of participation, hospitalizations, hemoglobin type, and age?

H1.) participants in face-to-face and online support would have higher mean self-care management resources than those in online groups only.
CHAPTER 3: METHODOLOGY

Participants

Participants were recruited from a variety of sources. Online recruitment was conducted through the use of social media websites such as Facebook and Reddit support groups for individuals with sickle cell disease. Approximately six support groups were sampled. Online support groups are asynchronous methods of communication that allow potentially thousands of members to interact while being physically separated. Participants were also recruited by contacting program directors of three organizations that served individuals with sickle cell disease. Participants were also recruited by enlisted in the help of health education counselors for the Department of Health and Human Services. Furthermore, personal networks, such as churches and networking at sickle cell conferences, were utilized. Through these recruitment methods, a total sample of 134 participants completed the survey. However, a total of 87 survey responses were eligible for analysis due to missing data.

Procedures

A non-experimental, nonequivalent group design was utilized for this study. Participants were recruited from five online support groups for individuals with SCD and three statewide organizations that serve the Sickle Cell Disease community. Criteria for participation was limited to adults 18 years of age or older, self-reported diagnoses of SCD, access to internet-connected device(s). Recruitment was accomplished by emailing recruitment information and online survey link through email listservs from three SCD organizations in central North Carolina. Online support groups were recruited by posting emailing recruitment information and online survey link. Participants received detailed informed consent forms requesting their participation in a
study about sickle cell disease, psychological well-being, and health-oriented social media usage.

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Adults with SCD who consented to participate in the study completed the online questionnaire. The online survey was hosted through Qualtrics. Participants who provided email addresses were entered into a sweepstake for ten $25 Amazon gift cards. Winning participants received compensation through email.

Measures

**Demographic questionnaire.** A demographic questionnaire survey participant, gender, hemoglobin type, age, race, healthcare utilization (frequency of emergency department-ED visits, hospitalizations in the past year), frequency of social media usage (i.e., per week and monthly), and length of time in the support group (months). See table 1 for demographic data.

**Social support.** Social support was assessed using the Social support survey (Sherbourne & Stewart, 1991). The Social support survey measures four types of support:
emotional/informational support, tangible support, positive social interaction, affectionate support, and structural support. This survey yields a composite score from a 19-item scale with subscales representing the aforementioned types of support. The internal consistency reliabilities were calculated at or above .91 (Sherbourne & Stewart, 1991).

**Sense of virtual community (SOVC).** The SOVC scale is a 18-item, four-point Likert-type instrument that assesses a sense of community in an online setting (Blanchard, 2008). The measure incorporates twelve internet-adapted items from the sense of community index (SCI) (version one of SCI-2) and ten items uniquely created to assess characteristics of VC (i.e., exchanging support and identification). A validation study of the measure was conducted using 256 participants across seven different online groups, including three listservs and four newsgroup forums. The study indicated high scale reliability overall, \( \alpha = 0.93 \). This measure is included as a measure of the perceived “quality” and connection the participant has to their online support group. The present study obtained a reliability score consistent with the validation study, \( \alpha = 0.911 \).

**Self-care ability.** Self-Care ability is defined as one’s “capability to engage in therapeutic behaviors to maintain and/or improve health status and quality of life” (Jenerette and Murdaugh, 2008, pg. 361) The appraisal of self-care agency scale was used to measure this concept. The appraisal of self-care agency scale is a 24-item five point likert type scale that calculates a composite score representing the participant’s self-care ability. Recent research indicates an internal consistency reliability range of .80 to.86. (Jenerette and Murdaugh, 2008).

**Self-efficacy.** Self-efficacy was measured using the self-efficacy for managing chronic disease short form 6 survey (SECD6). The SECD6 short form is a six-item questionnaire that assesses self-efficacy for coping with the physical and psychological consequences of chronic
illness/disease. The SECD6 ranks self-efficacy on the average of a 1 to 10-point scale, with 10 representing high confidence/efficacy. This measure is highly reliable, with an alpha value of (α=0.90) (Fan and Lv, 2016).

**Self-care management resources.** Jenrette and Murdaugh (2008) hypothesized that vulnerability factors such as health care utilization, socio-demographic variables, and frequency of pain crises had a negative impact on sickle cell patient outcomes, but that self-care management resources positively mediated this relationship. The present study defined self-care management resources (SCMR) as social support, self-efficacy, and self-care ability. Each analysis was run with the individuals scales representing self-care management resources.

**Health-related quality of life.** Health-related quality of life was assessed using the CDC HRQoL-4, which was developed by the Center for Disease Control and Prevention to assess physical and mental health in the general U.S population (Ford & Li, 2008; Hennessy et al., 1994). The CDC HRQoL-4 measures health-related quality of life based upon a four-item scale with lower scores indicating a higher quality of life. Sample questions include: “Would you say your health, in general, is excellent, very good, good, fair or poor?” and "Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" The CDC-HRQoL-4 has been validated in several studies, most notably in a sample of adults with arthritis. The CDC-HRQoL-4 scores were correlated with the SF-36 version 2 (Mielenz et al., 2006). For ease of analysis, quality of life was measured using the overall quality of life item. QoL overall asked participants "Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?".

**Support group participation.** Support group participation represented participants
involvement in face-to-face, online, online and virtual, and no support groups. were asked a yes or no question regarding their participation in face-to-face or traditional support groups. Participants were classified into one of three groups, F2F and online support groups, online support groups, and no support groups.

The intensity of online participation. This variable was calculated as a linear function of participant self-reported frequency and duration of online support group involvement (Figure 2).

Statistical Analyses

Data were analyzed using a variety of descriptive and inferential statistics. Demographic variables and vulnerability factors were analyzed for central tendency and variability. Correlational analysis was conducted to assess the strength of the relationship between self-care management resources, sense of community, sense of virtual community, and quality of life scores. An Independent-samples t-Test was conducted to assess the relationship between face-to-face (F2F) support group participation and SCMR. A one-way ANCOVA was used to determine differences in SCMR scores between F2F and online support groups and online only support groups with age, hospitalizations, and intensity of participation as covariates.

Sample Size

G Power analysis calculated for correlation, t-test, and ANCOVA tests revealed a required sample size of between 100 and 251 participants. Power analysis was conducted for both medium and large effect sizes based upon the findings of Leimeister, Schweizer, Leimeister, and Krcmar (2008) that within independent and dependent relating to internet usage (frequency and length of time);perceived advantages of internet usage for virtual communities had a moderate effect size in path analysis. Furthermore, social support and virtual relationship
variables had a high effect size in a path analysis study (Leimeister, Schweizer, Leimeister, and Krcmar, 2008). Significant challenges during recruitment were encountered. These impediments resulted in less than 100 participants with useable data for statistical analysis. Thus, statistical power was attenuated in this study due to the limited availability of participants accessible and willing to complete the online survey. The inability to recruit a large enough sample size reduced statistical power. Insufficient power may have resulted in a lack of treatment effects and statistical significance observed in most of the statistical analyses conducted in this study.

Challenges to recruitment included an inability to gain access to consenting participants, a lottery system for participant compensation (such that all participants were not compensated for participation), and cultural mistrust of researchers in some communities with sickle cell. Recruitment materials were distributed through email listservs created by local SCD organizations. Recruitment scripts for virtual support group participants were posted to online support group forums on a weekly basis for approximately six months.
CHAPTER 4: RESULTS

Descriptive Statistics

The primary dependent variable for this analysis was self-care management resources (SCMR) scores as measured by self-care ability, social support and self-efficacy. The mean overall health-related quality of life score was 9.88 days of poor physical or mental health, with a SD of 8.87. Total Sense of Community scores averaged 29.80, with a standard deviation of 20.38. Sense of Virtual Community has a mean of 2.99 and a standard deviation of .600. Table 1 and 2 further illustrates these descriptive statistics.

Demographic Statistics

Descriptive statistics were conducted to ascertain mean and frequency data for demographic variables. The mean age for the sample is 35.7 years old. The sample was 24.3% male and 75.7% female. Participants in the study were 89.3% African American, 2.7% Latino, 1.3% American Indian/Alaska Native, 4% Other/interracial, and 2.7% of the sample did not specify ethnic identity. Hemoglobin morphology was predominantly Hb-SS representing 63.2% of the sample, 24.1% Hb-SC, 8.0% Hb Beta-Thalassemia, and 2.4% other Hb types, and 3.4% did not know their hemoglobin type. The intensity of participation in support groups represents how frequent and the duration of participation in support groups, with a minimum score of 1 and 14 indicating intense participation. The intensity of participation mean was 10.70 (SD= 2.60). Research participants were members of F2F and online support groups (N=17), online groups (N=50), and no support group (N=8). See table 3 for more details.

Hypothesis Testing

Statistical analysis was conducted to address key research questions and test the primary
hypotheses of this study. The first research question was: What is the relationship between participation in support groups and self-care management resources? It was hypothesized that Support group participants will report higher mean SCMR scores (self-care ability, social support, and self-efficacy) than those in no support group. An Independent samples t-test was conducted to assess the relationship between support group participation and SCMR. Data analysis indicated that there was no significant difference in self-care ability between participants in support groups (n=76, m= 94.01) and no support group (n=11, m= 90.19), t(85)= -.924, p=.358). There was no significant difference in social support scores between participants in support groups (n=75, m= 3.61) and no support group (n=11, m= 3.45), t(15.721)= -.385, p=.701). A Levene’s test of equality of variances indicated that equal variances could not be assumed. Thus, a Mann Whitney U was conducted, U=.104, p=ns. Moreover, there was no significant difference in self-efficacy scores between participants in support groups (n=76, m= 6.08) and no support group (n=11, m= 6.77), t(85)= 1.02, p=.312).

Research questions number two sought to understand the relationship between sense of community and self-care management resources (self-care ability, social support, and self-efficacy). It was hypothesized that sense of community index (SOC) scores would be positively correlated with self-care management resources scores. A Pearson correlation was conducted to assess this relationship. Data analysis indicated self-care ability was not significantly correlated with sense of community scores, r(100)=.090, p=.247. See table 4 for details. A Pearson correlation was conducted to assess the strength of the relationship between social support and sense of community scores. Data analysis indicated that social support was not significantly correlated with total sense of community scores, r(100)=.084, p=.262. However, there was a significant positive correlation between social support scores and the influence subscale of sense...
of community, \( r(50) = .240, p < .05 \). See table 5 for details. Data analysis also indicated that self-efficacy was not significantly correlated with total sense of community scores, \( r(60) = .187, p = .077 \). However, there was a significant positive correlation between self-efficacy scores and sense of community reinforcement of needs subscale, \( r(56) = .241, p < .05 \); membership subscale, \( r(60) = .233, p < .05 \); influence subscale, \( r(50) = .248, p < .05 \); and shared emotional connection subscale, \( r(48) = .324, p < .05 \). See table 6 for details.

Furthermore, it was that sense of virtual community scores will be positively correlated with each self-care management resource scores (self-care ability, social support, self-efficacy) A Pearson correlation revealed that Self-care ability was significantly correlated with sense of virtual community, \( r(74) = .201, p < .05 \). Data analysis also revealed that social support scores were significantly correlated with sense of virtual community, \( r(74) = .319, p < .01 \). Pearson correlation also revealed that social support scores were significantly correlated with sense of virtual community, \( r(74) = .286, p < .01 \). See table 7 for details.

Research question number three examined the relationship between Self-care Management Resources scores and overall health-related quality of life (HRQoL) scores. It was hypothesized that there would be a negative relationship between self-care management resource scores and Health-Related Quality of life (HRQoL) scores. A Pearson correlation was conducted to assess this relationship. Data analysis revealed self-care ability was not significantly correlated with overall quality of life scores, \( r(80) = -.107, p = .173 \). Social support was negatively correlated with overall quality of life scores, \( r(80) = -.267, p < .05 \). This analysis suggests that higher social support scores were associated with fewer days of poor physical and mental health. Self-efficacy was negatively correlated with overall quality of life scores, \( r(80) = -.399, p = .001 \). This analysis suggests that higher self-efficacy scores were associated with fewer days of poor physical and
mental health. See table 8 for details.

Research question number four questioned, are there differences in self-care management resources between participants in F2F and online groups and online groups when controlling for the length of time they have been in the group, frequency of participation, and demographic variables? It was hypothesized that participants in no face-to-face support group and no virtual support group would have lower mean self-care management resources than those in face-to-face or virtual support groups. An ANCOVA was conducted to test this hypothesis. Hemoglobin type, age, intensity of participation, and hospitalizations per year were covariates. Data analysis indicated that there was no significant difference in self-care ability between participants in online groups (N= 50, M=93.29) and F2F and online groups (N= 17, M=98.35), F[1, 61]= 2.689, p=.106. See Tables 9 for details. There was no significant difference in social support between participants in online groups (n= 50, M=3.45) and F2F and online groups (n=17, M=3.96), F[1, 61]= 2.766, p=.212. See table 10 for details. Furthermore, there was no significant difference in self-efficacy between participants in online groups (n= 50, M=6.03) and F2F and online groups (n=17, M=6.57), F[1, 61]= .542, p=.464. See table 11 for details. Although, it should be observed that the F2F and online support group participants had positive and higher mean SCMR scores than participants in online support groups only. Results indicated that there was no statistically significant difference in SCMR scores between online only and F2F & online support group participation.

Completers vs Non-completers

During data collection, it was observed that data were missing throughout the dataset. Data were excluded listwise as the default setting in SPSS. This method can result in a smaller
sample size and larger standard errors, but was the best option given other alternatives. Imputation of missing values was considered but rejected due to the disadvantages of doing so. Broadly speaking, single imputation and multiple imputation are viable options for addressing missing data. Single imputation is advantageous when less than 5% of data are missing. Given the greater percentage of missing data in this study, single imputation would underestimate the standard error. Likewise, multiple imputation would generate multiple datasets and increase estimated standard error.

To assess how missing data effected the results of this study a series of completer vs non-completer analyses were conducted. Completer and non-completer was defined by the variable “finished.” It measured whether participants had completed the entire survey. The variable was a dichotomous yes or no. There were a total of 129 participants that completed the survey. Approximately 78 participants fully completed the survey and 51 participants did not fully complete the survey.

A Chi-square test of independence was conducted to assess differences in emergency room visits between completers and non-completers. There were no significant differences in ER visits between completers (n=78) and non-completers(n=40), $X^2(6, N=118) = 7.307$, $p=.293$. A Chi-square test of independence was also conducted to assess differences in hospitalizations per year between completers and non-completers. There was a significant differences in hospitalizations between completers (n=78) and non-completers(n=40), $X^2(4, N=118)= 14.118$, $p< .01$. A Chi-square test of independence also indicated that there was a significant differences in hospitalizations between completers (n=78) and non-completers(n=40), $X^2(4, N=118)= 15.821$, $p< .01$. Analysis indicated that 50 completers had HbSS and 16 non-completers had HbSS. Interestingly, non-completers(n=10) were more likely to report not knowing their
hemoglobin type than completers (n=3). Moreover, there was a significant differences in hospitalizations between completers (n=78) and non-completers (n=40), $X^2(4, N=118)= 15.821$, $p< .01$. Lastly, A Mann-Whitney U revealed that there was a significant difference in self-care ability between completers (n=78, M= 53.62) and non-completers, (n=22, M=39.43), $U(n=100)= 614.5$, $p< .05$. There were no statistically significant differences between completers and non-completers in sense of community, sense of virtual community, social support, and self-efficacy.

Analyses of all variables between the completers and the non-completers revealed that there were few patterns in survey completion and missing data between completers and non-completers. It was observed that completers experienced greater vulnerability factors than non-completers. Specifically, non-completers were more likely to not know their hemoglobin type than completers. Completers also reported higher self-care ability scores than non-completers. These results suggest completers may have greater awareness of their condition and take steps to ameliorate its effects than non-completers.
CHAPTER 5: DISCUSSION

Sickle cell disease is one of the most common genetically heritable conditions. It is estimated that nearly 1 in 500 African American in the United States has the disease (CDC, 2018). SCD is a genetically inheritable medical condition associated with debilitating pain and chronic anemia that can result in negative biopsychosocial consequences. Support groups have been shown to assist in the management of numerous chronic medical conditions, such as rheumatoid arthritis, breast cancer, ALS, and fibromyalgia (Hesselink et al., 2004, Willis, 2014).

The purpose of this study was to understand better how individuals with Sickle Cell Disease use virtual support group communities and traditional face-to-face support groups to enhance self-care management resources such as social support, self-efficacy, self-care ability, and sense of community. This study also sought to compare the effectiveness of virtual communities versus face-to-face support groups to help patients cope with the disease by strengthening self-care management resources. An Independent-Samples t-Test was conducted to assess the relationship between support group participation and self-care management resources (SCMR). A factorial ANCOVA was used to determine differences in SCMR scores between face-to-face support groups and online support groups with demographic variables and intensity of participation as covariates. The findings revealed that participants in support groups did not have higher SCMR scores than those who were not in support groups. In addition, SCMR is not significantly associated with support group type. The implications of this finding have far-reaching applications for SCD patients and health care professionals.

The initial hypothesis proposed that participants that were members of any support group would report higher mean SCMR scores than those in no support group. An independent samples t-test was conducted. Data analysis revealed that there were no statistically significant mean
differences in SCMR scores between groups. Results indicated that support group participation was not significantly related to any self-care management resources. This suggests that support groups alone may not be the only contributors to self-care management resources. Given that this is the first study to examine these relationships in a sample of people with SCD, the limitations of the study prevent us from making any firm conclusions regarding the value of support group participation, either virtual or face-to-face. The lack of evidence to support this hypothesis is surprising given the findings of past research. For instance, Willis’ (2014) investigation of social support among adults with arthritis found that support groups offered its members a variety of emotional, informational and tangible social support. The current study does not provide evidence to support this finding among adults with sickle cell disease. There are several methodological explanations available to elucidate this discrepancy. Increased sample size and experimental methods may have yielded statistically significant results. Further research is needed to assess the relationship between any support group type participation and self-care management resources for alleviating the effects of SCD.

Hypothesis number two postulated that Sense of Community Index (SOC) scores would be positively correlated with self-care management resources scores. Data analysis indicated that Sense of Community Index (SOC) and self-care management resources were statistically significant and positively correlated across all SOC index subscales: reinforcement of needs, membership, influence, shared emotional communication, and overall SOC. These results suggest that there is a linear relationship between self-care management resources, social support, self-efficacy, self-care ability, and participant sense of community. This correlation was positive yet not significant for SCMR and Sense of Virtual Community scores. Moreover, this suggests that a greater sense of connectedness and belongingness to online support groups is
associated with higher ratings of self-care management resources. This further validates the positive relationship between social support and self-efficacy on sense of community in populations with a chronic medical condition, as reported by Willis (2014) in a sample of 8231 online support group members with arthritis as well as Hesselink and colleagues’ (2004) investigation of patients with asthma and COPD. Conversely, there was no relationship between higher self-care management resources and sense of community. Past research indicated that a higher sense of belongingness and group satisfaction to one’s face to face support group would be associated with higher social support and self-efficacy scores (Telfair and Gardner, 1999). The results of the present study did not support this relationship. This was the first study to assess how self-care management resources and sense of community may be related to face-to-face support group participation in a sample with SCD. It is possible that F2F support groups do not offer participants sufficient interactions or “dosage” to produce an effect on self-care management resources.

Additionally, it was hypothesized that there would be a negative relationship between self-care management resources scores and Health-Related Quality of Life (HRQoL) scores. A Pearson correlation suggested that a significant and overall negative relationship exists between Self-care management resources and Health-related Quality of Life scores. Health-related quality of life overall is a linear construct that represents the number of days in the last 30 that the poor physical or mental health interfered with daily life activities. In other words, higher HRQoL scores indicate poorer physical and psychological health. This trend was also observed between higher self-efficacy and social support scores and fewer days of poor physical health, poor mental health, and physical health status. Although, the methodological design and statistical limitations of this study impede the ability to make causal inferences regarding the effect of self-
care management resources on health-related quality of life. Study data proposed that individuals with sickle cell disease that have greater self-care management resources, such as social support, self-efficacy, and self-care behaviors, report fewer days of poor physical and mental health. Past research has indicated that support groups offer an effective platform for members to exchange social support and improve self-efficacy (Mann-Jiles & Morris, 2009; Telfair and Gardner, 1999). The results of the present study expand on research conducted by Mann-Jiles & Morris (2009), which found that patients with SCD had lower mean quality of life scores compared to healthy populations. The present study provides some evidence to support the role of self-care management resources in promoting better health-related quality of life among adults living with sickle cell disease. Additionally, this study substantiated the benefits of self-care management resources to health outcomes, such as quality of life as proposed in the theory of self-care management resources for sickle cell disease by Jenerette & Murdaugh (2008).

Hypothesis four postulated that participants in face-to-face and online support would have higher mean self-care management resources than those in online groups only. Results indicated that there was no statistically significant difference in SCMR scores between F2F & online support groups and online support group members. Past research suggested that participation in support groups are an effective method of exchanging social support, self-care behaviors, and enhancing self-efficacy for individuals with chronic medical conditions (Huh et al., 2014; Loane & D’Alessandro, 2013). F2F and online group participants reported higher self-care management resource scores than online only participants, though not statistically significant. It is possible that there is a benefit to dual support group participation. Future research should more closely examine this relationship.

The current study results are corroborated by past research conducted by Telfair and
Gardner’s (1999) regression analysis with group satisfaction (high vs. low) and psychological well-being. Statistical analysis suggested that participants who were members of a support group (face-to-face) and rated high group satisfaction reported higher levels of psychological well-being (Telfair and Gardner, 1999, p. 384). Telfair and Gardner’s investigation suggests that participant satisfaction with membership in support groups may improve psychological well-being. These results corroborate the current study’s findings that sense of virtual community was associated with higher self-care management resources and may indicate that the quality of membership in support groups matters. That is to say that, positive regard and belongingness to support groups are related to positive mental and physical outcomes for individuals living with sickle cell.

Establishing effective resources for managing the deleterious effects of sickle cell disease can improve the overall quality of life and biopsychosocial well-being of adult patients. Past research has labeled sickle cell disease as a syndrome, a characterization that indicates the multifaceted impact it has on the lives of patients (Edwards et al., 2005). The complex physiological, psychological, and social effects of SCD make it a difficult illness for patients to manage throughout the stages of lifespan development. As such, it is imperative that strategies for self-care be employed. The current study adds to the literature in a variety of ways. Online and face-to-face support groups may be an effective tool SCD patients can use to employ self-care behavior strategies to manage medications, pain, fatigue, and other physical symptoms. Moreover, psychosocial symptoms such as anxiety, depression, and isolation can be ameliorated through the social support afforded by support groups. The findings also corroborate with those of several other studies (Hesselink et al., 2004, Huh et. al., 2014, Josefsson et. a., 2005, Willis, 2015), solidifying the idea that social support groups are an effective self-care tool for
individuals suffering from chronic illnesses.

**Limitations**

The small sample size was a major limiting factor for this study. Over the course of six months, only 135 individuals participated in the survey. Of those, only 84 had completed all survey questions. Various challenges during recruitment were encountered. These hindrances resulted in less than 100 participants with useable data for statistical analysis. Thus, statistical power was attenuated in this study due to the limited availability of participants accessible and willing to complete the online survey. Challenges to recruitment included an inability to gain access to consenting participants, a lottery system for participant compensation (such that all participants were not compensated), and cultural mistrust of scientists and researchers in African American communities. Recruitment materials were distributed through listservs created by local SCD organizations. Recruitment scripts for virtual support group participants were posted to online support group forums on a weekly basis for approximately six months.

The effects of the small sample size were further exacerbated by missing data for key variables such as social support, SOC, SOVC, QoL, and other variables. This issue was addressed by filtering the data based upon participation in any support group. Comparatively, similar studies on chronic medical conditions and support groups had larger sample sizes such as Willis’(2014) that sampled 8321 participants with rheumatoid arthritis, Hesselink and colleagues’(2004) investigation of 273 patients with asthma and COPD, and Fan & Lv’s (2016) examination of self-efficacy among 159 participants in a support group for chronic heart failure.

Moreover, there are barriers to conducting research in minority populations, such as African Americans or Latino Americans, which have higher prevalence rates of sickle cell
disease (George, Duran, & Norris, 2014). The historical relationship between minority communities, particularly African Americans and the scientific community, is fraught with racism, ethical violations, exploitation, and malfeasance. (George, Duran, & Norris, 2014; Bridges & Cooper, 2014; Horowitz et al., 2009). Given this tenuous relationship finding research participants can be difficult. Telfair & Gardner’s (1999) examination of psychological well-being, physical symptoms, and group satisfaction among adolescents with sickle cell disease exemplifies this difficulty. The researchers were only able to sample 99 participants for their scientific inquiry.

The current study also had limitations to internal validity. A cross-sectional, non-experimental, nonequivalent group design was utilized to answer research questions and the overall research goal. Several threats to validity further reduced the ability to make causal inferences. Participants' involvement in face-to-face and/or virtual support groups was not due to having been randomly assigned, but rather self-selection through preexisting groups. Therefore, a selection threat was present, as well as a numerical imbalance between support group participation conditions.

The present study also had a few threats to external validity. Participants were recruited through various advertisements on email listservs and online support group postings. No probability sampling methods were employed. Survey respondents were sampled using the nonprobability convenience sampling method. Adults living with sickle cell who responded to study advertisements and consented to complete the survey were included in this sample. In utilizing this sampling method, it is possible that the present sample and data are not representative of the adult population with SCD. Additionally, the present study oversampled online support groups and utilized an online survey exclusively. However, a moderate proportion
of participants were members of both online and face-to-face support groups. Thus, a sampling bias and selection threat limit external validity and our ability to generalize to the entire sickle cell disease population.

**Future Research**

Future studies should be conducted to explore how support group type, whether face-to-face or online, impact psychological well-being among adults with SCD. Studies utilizing experimental methodologies will further enhance our ability to develop effective psychosocial interventions for individuals living with sickle cell disease. Potential research should also assess best practices in the design of online support groups and social media platforms. Specifically, this research should investigate which features and characteristics of virtual support groups facilitate the effective exchange of social support and self-care management techniques for individuals with sickle cell disease. A longitudinal designed could be utilized to assess how support group participation can improve self-care management resources among individuals with SCD as well as the dosage needed to produce a treatment effect. For example, what level of interaction (frequency and duration) with support group members and what type of social support will improve self-care management resources? Is a combination of online and face to face support groups most effective, or is any support group participation effective? What type of support programming will improve self-care management resources? Participants could be randomly assigned to either a F2F group, online group, or F2F and online support group for a period of six to 12 months. Dosage effects could be assessed by randomly assigning participants to interact in groups, 1 time a month, 2 times a month, and 3 times a month for six to twelve months.
**Practical Implications**

Sickle cell clinics and hematology clinics often maintain relationships with non-profit organizations that serve SCD patients. Many non-profit SCD organizations maintain traditional support groups and other forms of assistance for patients. Healthcare providers and SCD organizations could create online support groups for SCD patients that utilize best practices for forum design to maximize user engagement, offer accurate medical information, and provide a range of self-care management techniques. Moreover, provider networks frequently employ psychologists, social workers, and other mental health professionals who can provide psychosocial support for the aforementioned online support groups. Healthcare providers could encourage patients to join online support groups as an extension of a plan for care. Additionally, action research that bridges the gap between healthcare professionals and patients represents an opportunity to serve communities with sickle cell by offering holistic approaches that meet the psychological, social, and physical needs of patients.

**Conclusion**

This study expands on the research that self-care management resources have a positive effect on the quality of life among individuals living with sickle cell. The present investigation also suggests that having a greater sense of community in one’s support group is associated with higher self-care management resources. Despite methodological limitations, this inquiry suggests that support groups benefit adults living with SCD to exchange social support, self-care behaviors, and help manage negative physical symptoms. As the use of computer-mediated technologies increases more individuals with SCD and a variety of other chronic illnesses will likely utilize online support groups in lieu of traditional support groups. This will create new opportunities for individuals with sickle cell disease and healthcare professionals to improve
physiological and psychosocial outcomes.
REFERENCES


Bonsaksen, T., Lerdal, A., & Fagermoen, M. S. (2012). Factors associated with self-efficacy in


Willis, E. (2014). The making of expert patients: The role of online health communities in

doi:10.1177/1359105313496446

### TABLES AND FIGURES

**Table 1**

*Self-care management resource means by support group.*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Online group</th>
<th>Face-to-face and online</th>
<th>No group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
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<td>50</td>
<td>93.28*</td>
<td>12.01</td>
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<tr>
<td>Social support</td>
<td>50</td>
<td>3.45</td>
<td>1.34</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>50</td>
<td>6.03</td>
<td>1.84</td>
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</table>

* Mean on a five point Likert type scale is 3.88, .50(SD)

**Table 2**

*Means and reliability for dependent variables.*

<table>
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<tr>
<th>Scale</th>
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<th>M</th>
<th>SD</th>
<th>Item #</th>
<th>Cronbach</th>
</tr>
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<td>16.48</td>
<td>24</td>
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<tr>
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<td>86</td>
<td>3.89</td>
<td>1.24</td>
<td>20</td>
<td>.981</td>
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<td>Self-efficacy</td>
<td>87</td>
<td>6.17</td>
<td>2.10</td>
<td>6</td>
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<tr>
<td>Sense of virtual community</td>
<td>74</td>
<td>2.99</td>
<td>.60</td>
<td>18</td>
<td>.911</td>
</tr>
<tr>
<td>Sense of community</td>
<td>60</td>
<td>29.38</td>
<td>20.38</td>
<td>25</td>
<td>.971</td>
</tr>
<tr>
<td>Overall quality of life</td>
<td>80</td>
<td>9.88</td>
<td>8.87</td>
<td>3</td>
<td>.820</td>
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</tbody>
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Table 3

Demographic variables by support group type.

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<thead>
<tr>
<th>Demographic Variable</th>
<th>Online group</th>
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<th>No group</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Hemoglobin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbSS</td>
<td>42</td>
<td>48.3</td>
<td>9</td>
</tr>
<tr>
<td>HbSC</td>
<td>12</td>
<td>13.8</td>
<td>7</td>
</tr>
<tr>
<td>Hb Beta Thalasemia</td>
<td>2</td>
<td>2.3</td>
<td>3</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
<td>15.4</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>38</td>
<td>48.7</td>
<td>13</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0x yearly</td>
<td>3</td>
<td>3.4</td>
<td>4</td>
</tr>
<tr>
<td>1-2x yearly</td>
<td>24</td>
<td>27.6</td>
<td>9</td>
</tr>
<tr>
<td>3-4x yearly</td>
<td>16</td>
<td>18.4</td>
<td>3</td>
</tr>
<tr>
<td>5-6x yearly</td>
<td>9</td>
<td>10.3</td>
<td>3</td>
</tr>
<tr>
<td>6+ yearly</td>
<td>4</td>
<td>4.6</td>
<td>0</td>
</tr>
<tr>
<td>ER visits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 times</td>
<td>2</td>
<td>2.3</td>
<td>3</td>
</tr>
<tr>
<td>1-2x monthly</td>
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<td>8.0</td>
<td>2</td>
</tr>
<tr>
<td>3-4x monthly</td>
<td>5</td>
<td>5.7</td>
<td>2</td>
</tr>
<tr>
<td>4+ Monthly</td>
<td>2</td>
<td>2.3</td>
<td>0</td>
</tr>
<tr>
<td>1-2x yearly</td>
<td>21</td>
<td>24.1</td>
<td>5</td>
</tr>
<tr>
<td>3-4x yearly</td>
<td>13</td>
<td>14.9</td>
<td>4</td>
</tr>
<tr>
<td>4+ yearly</td>
<td>6</td>
<td>6.9</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 4

Pearson correlation between self-care ability and sense of community scores.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-Care Ability</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Total Sense of Community</td>
<td>.090</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sense of Community-Reinforce Needs</td>
<td>.115</td>
<td>.840*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Sense of Community- Membership</td>
<td>.128</td>
<td>.906*</td>
<td>.698*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sense of Community- Influence</td>
<td>.135</td>
<td>.937*</td>
<td>.856*</td>
<td>.797*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Sense of Community-Shared Emo</td>
<td>.085</td>
<td>.912*</td>
<td>.903*</td>
<td>.696*</td>
<td>.862*</td>
<td></td>
</tr>
</tbody>
</table>

Note: *Correlation is significant at the .01 level (1-tailed).
Table 5

Correlation between social support and sense of community scores.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Social Support</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Total Sense of Community</td>
<td>.084</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sense of Community-Reinforce Needs</td>
<td>.147</td>
<td>.840**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Sense of Community- Membership</td>
<td>.161</td>
<td>.906**</td>
<td>.698**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sense of Community- Influence</td>
<td>.240*</td>
<td>.937**</td>
<td>.856**</td>
<td>.797**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Sense of Community-Shared Emotional Connection</td>
<td>.172</td>
<td>.912**</td>
<td>.903**</td>
<td>.696**</td>
<td>.862**</td>
<td></td>
</tr>
</tbody>
</table>

Note: *Correlation is significant at the .05 level (1-tailed).
**Correlation is significant at the .01 level (1-tailed).

Table 6

Correlation between self-efficacy and sense of community scores.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-Efficacy</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Total Sense of Community</td>
<td>.187</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sense of Community-Reinforce Needs</td>
<td>.241*</td>
<td>.840**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Sense of Community- Membership</td>
<td>.233*</td>
<td>.906**</td>
<td>.698**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sense of Community- Influence</td>
<td>.248*</td>
<td>.937**</td>
<td>.856**</td>
<td>.797**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Sense of Community-Shared Emotional Connection</td>
<td>.324*</td>
<td>.912**</td>
<td>.903**</td>
<td>.696**</td>
<td>.862**</td>
<td></td>
</tr>
</tbody>
</table>

Note: *Correlation is significant at the .05 level (1-tailed).
**Correlation is significant at the .01 level (1-tailed).

Table 7

Correlation between self-care management resources and sense of virtual community.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-care Ability</td>
<td>100</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Social Support</td>
<td>87</td>
<td>.520**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Self-Efficacy</td>
<td>86</td>
<td>.461**</td>
<td>.472**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>4. Sense of Virtual Community</td>
<td>74</td>
<td>.201*</td>
<td>.286**</td>
<td>.319**</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: *Correlation is significant at the .05 level (1-tailed).
**Correlation is significant at the .01 level (1-tailed).
Table 8

Correlation between self-care management resources and quality of life.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Self-care Ability</td>
<td>100</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Social Support</td>
<td>86</td>
<td>.461*</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Self-Efficacy</td>
<td>87</td>
<td>.520**</td>
<td>.472**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Overall Quality of Life</td>
<td>80</td>
<td>-.107</td>
<td>-.267**</td>
<td>-.399**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Physical Health Status</td>
<td>81</td>
<td>-.376**</td>
<td>-.467**</td>
<td>-.310**</td>
<td>.475**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Physical Quality of Life</td>
<td>81</td>
<td>-.154</td>
<td>-1.178</td>
<td>-.271**</td>
<td>.597**</td>
<td>.499**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>7. Mental Quality of Life</td>
<td>81</td>
<td>-.213*</td>
<td>-.325**</td>
<td>-.274**</td>
<td>.577**</td>
<td>.430**</td>
<td>.661**</td>
<td>-</td>
</tr>
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Note: *Correlation is significant at the .01 level (1-tailed).
**Correlation is significant at the .01 level (1-tailed).

Table 9

ANCOVA between self-care ability and support group participation.

<table>
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<tr>
<th>Source</th>
<th>df</th>
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<th>MS</th>
<th>F</th>
<th>p</th>
<th>η²</th>
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</thead>
<tbody>
<tr>
<td>Self-care ability</td>
<td>1</td>
<td>363.49</td>
<td>363.49</td>
<td>2.689</td>
<td>.106</td>
<td>.042</td>
</tr>
<tr>
<td>Hemoglobin type</td>
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<td>340.36</td>
<td>340.36</td>
<td>2.518</td>
<td>.118</td>
<td>.040</td>
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<tr>
<td>Hospitalizations</td>
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<td>190.90</td>
<td>190.90</td>
<td>1.412</td>
<td>.239</td>
<td>.023</td>
</tr>
<tr>
<td>Intensity of participation</td>
<td>1</td>
<td>555.14</td>
<td>555.14</td>
<td>4.106</td>
<td>.047</td>
<td>.063</td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>27.55</td>
<td>27.55</td>
<td>.204</td>
<td>.653</td>
<td>.003</td>
</tr>
<tr>
<td>Within groups</td>
<td>61</td>
<td>8246.39</td>
<td>135.19</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>608998.00</td>
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<td></td>
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</tr>
</tbody>
</table>

Table 10

ANCOVA between social support and support group participation.

<table>
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<tr>
<th>Source</th>
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<th>SS</th>
<th>MS</th>
<th>F</th>
<th>p</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>1</td>
<td>2.77</td>
<td>2.77</td>
<td>1.588</td>
<td>.212</td>
<td>.025</td>
</tr>
<tr>
<td>Hemoglobin type</td>
<td>1</td>
<td>.424</td>
<td>.424</td>
<td>.244</td>
<td>.623</td>
<td>.004</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>1</td>
<td>1.522</td>
<td>1.522</td>
<td>.874</td>
<td>.353</td>
<td>.014</td>
</tr>
<tr>
<td>Intensity of participation</td>
<td>1</td>
<td>1.312</td>
<td>1.312</td>
<td>.753</td>
<td>.389</td>
<td>.012</td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>.645</td>
<td>.645</td>
<td>.370</td>
<td>.545</td>
<td>.006</td>
</tr>
<tr>
<td>Within groups</td>
<td>61</td>
<td>106.21</td>
<td>1.741</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>113.22</td>
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</table>
**Table 11**

**ANCOVA between self-efficacy and support group participation.**

<table>
<thead>
<tr>
<th>Source</th>
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<th>SS</th>
<th>MS</th>
<th>F</th>
<th>p</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between groups</td>
<td>1</td>
<td>2.207</td>
<td>2.207</td>
<td>.542</td>
<td>.464</td>
<td>.009</td>
</tr>
<tr>
<td>Hemoglobin type</td>
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<td>2.088</td>
<td>.513</td>
<td>.477</td>
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Figure 1

Visual relationship between vulnerability factors, support groups, SCMR, and QoL.

Figure 2

Computational model of the relationship between support groups, self-care management resources and quality of life.
APPENDICES
Appendix A

North Carolina State University
INFORMED CONSENT FORM for RESEARCH

Title: The Role of Support Groups Among Individuals with Sickle Cell Disease

Primary Investigator: Jeffrey L. Wilkins                         Faculty Sponsor: Dr. Craig C. Brookins

What are some general things you should know about research studies?

You are being asked to take part in a research study. Your participation in this study is completely voluntary. You have the right to be a part of this study, to choose not to participate, or to stop participating at any time without penalty. The purpose of this research study is to understand how people with sickle cell use online and face-to-face support groups to find social support and self-care techniques. This research will hopefully help understand how people with sickle cell use support groups and how we can make their life better by improving support groups.

You are not guaranteed any personal benefits from being in a study. Research studies also may pose risks to those that participate. In this consent form, you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form, it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above.

Purpose of the Study

The purpose of this study is to examine how people with sickle cell use online and face-to-face support groups to find social support and self-care techniques. This research will hopefully help me to understand how people with sickle cell use support groups and how we can make their life better by improving support groups.

Study Protocol

If you agree to participate in this study, you will be asked to complete a questionnaire that asks you questions about your demographics, internet/social media usage, support group participation, social support and self-care techniques, sense of community, and your quality of life. The study should take about 15 minutes to complete.

Risks
This study will ask questions regarding social support, interactions with others online and/or face to face, and your experience with sickle cell disease which may be difficult for some to reflect on. If any question in this study causes you distress, you are free to end participation and are encouraged to consult the University Counseling Center at North Carolina State University.

Counseling Center - Suite 2401
2815 Cates Avenue
Campus Box 7312
Raleigh, North Carolina 27695
919-515-2423
http://healthcenter.ncsu.edu/counseling-center

Benefits
Knowledge resulting from your participation in this study may increase our understanding of how support groups can improve the quality of life of people living with sickle cell disease.

Confidentiality
The information in the study records will be kept confidential to the full extent allowed by law. Data will be stored securely in password-protected files on a password-protected computer that only the primary investigator has access to. No reference will be made in oral or written reports which could link you to the study. You will NOT be asked to write your name on any study materials so that no one can match your identity to the answers that you provide.

Compensation

What if you have questions about this study?

If you have questions at any time about the study or the procedures, you may contact the researcher.

Jeffrey L. Wilkins
jlwilkin@ncsu.edu
704-619-1334

Craig C. Brookins, Ph.D. (faculty advisor)
biadnow@ncsu.edu

What if you have questions about your rights as a research participant?
If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this study, you may contact Deb Paxton, Regulatory Compliance Administrator for the NCSU Institutional Review Board at dapaxton@ncsu.edu or by phone at 919-515-4514.

Consent to Participate

“I have read and understood the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may choose not to participate or to stop participating at any time without penalty or loss of benefits to which I am otherwise entitled.”

_____I agree
_____I do not agree

Please enter email address below.
(Email here) __________________________

By starting the survey you are consenting to participate in this study
Appendix B

Recruitment Script- Sickle Cell and Support Groups Study

Hello, my name is Jeff Wilkins and I am a doctoral student at NC State University conducting my doctoral dissertation research. I am studying how people with sickle cell use online and face-to-face support groups to find social support and self-care techniques. This research will hopefully help me to understand how people with sickle cell use support groups and how we can make their life better by improving support groups.

If you volunteer as a participant in this study, you will be asked to complete a survey that asks you questions about your demographics, internet/social media usage, support group participation, social support and self-care techniques, sense of community, and your quality of life.

The survey should take about 10-15 minutes to complete. I would like to assure you that this study has been reviewed and received ethics clearance by the Institutional Review Board at NC State University.

If you are interested in participating, please click on or enter the website URL link below, read and agree to the informed consent form and complete the survey.

Survey link: https://ncsu.qualtrics.com/jfe/form/SV_b4oOZU8hf6IOKG1

Thank you for your time and participation.

Jeffrey L. Wilkins, MA
Doctoral Candidate
North Carolina State University
Department of Psychology
jlwilkin@ncsu.edu
Appendix C

Sickle Cell Disease Study Questionnaire

Demographic Survey

Q1 What is your Sex
- Male (1)
- Female (2)

Q2 What is your age?
- 18 - 24 (1)
- 25 - 34 (2)
- 35 - 44 (3)
- 45 - 54 (4)
- 55 - 64 (5)
- 65 - 74 (6)
- 75 or older (7)

Q3 What is your race/ethnicity?
- White (1)
- Black or African American (2)
- Hispanic or Latinx (3)
- American Indian or Alaska Native (4)
- Asian (5)
- Native Hawaiian or Pacific Islander (6)
- Other/interracial (7)

Q4 What is your Hemoglobin type?
- HbSS (1)
- HbSC (2)
- Hb Beta-Thalassemia (3)
- HbSD, HbSE, or HbSO (4)
- I don't know (5)

Q5 How frequently do you have to visit the Emergency room (or infusion center) for a Sickle Cell Pain crisis or complications?
- 1-2 times a month (1)
- 3-4 times a month (2)
- More than 4 times a month (3)
- 1-2 times a year (4)
- 3-4 times a year (5)
- More than 4 times a year (6)

Q6 How many times a year are you hospitalized due to Sickle Cell Disease and its complications?
- 1-2 times (1)
- 3-4 times a year (2)
- 5-6 times a year (3)
- More than 6 times a year (4)

Q7 How many times a week to you use online support groups for Sickle Cell, such as groups on Facebook, sickle cell websites/forums?
- Once a week (1)
- 2-3 times a week (2)
- 4-6 times a week (3)
- Daily (4)

Q8 How long, in months, have you been a member of the above-mentioned online groups?
- 1-3 months (1)
- 4-6 months (2)
- 6-9 months (3)
- 9-12 months (4)
- 12-24 months (5)
- More than 24 months (6)

Q9 Are you a member of a Face-to-face support group for Sickle Cell?
- Yes (1)
- No (2)

Q10 If you are a member of a face-to-face support group for Sickle Cell, how long have you been a member of this group?
- 1-6 months (1)
- 6-12 months (2)
- 12-24 months (3)
- More than 24 months (4)
Self-Efficacy Survey:

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

Q11 How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

Q12 How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

Q13 How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

Q14 How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)
Q15 How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

Q16 How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life? Rate on a 1-10 scale, 1-being not at all confident, 10-being totally confident

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 (6)
- 7 (7)
- 8 (8)
- 9 (9)
- 10 (10)

Social support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Choose one number from each line. 1-5, 1- None of the time, 5- All of the time.

Q18 Someone you can count on to listen to you when you need to talk.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q19 Someone to give you information to help you understand a situation.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q20 Someone to give you good advice about an (emotional/social/physical) crisis.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q21 Someone to confide in or talk to about yourself or your problems.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)
Q22 Someone whose advice you really want.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q23 Someone to share your most private worries and fears with.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q24 Someone to turn to for suggestions about how to deal with a personal problem.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q25 Someone who understands your problems.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q26 Someone to help you if you were confined to bed.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q27 Someone to take you to the doctor if you needed it.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q28 Someone to prepare your meals if you were unable to do it yourself.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q29 Someone to help with daily chores if you were sick.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q30 Someone who shows you love and affection.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q31 Someone to love and make you feel wanted.

- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)
Q32 Someone who hugs you.
- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q33 Someone to have a good time with.
- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q34 Someone to get together with for relaxation.
- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q35 Someone to do something enjoyable with.
- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Q36 Someone to do things with to help you get your mind off things.
- None of the time (1)
- A little of the time (2)
- Some of the time (3)
- Most of the time (4)
- All of the time (5)

Quality of Life Scale
Q37 Would you say that in general, your health is:
- Excellent (1)
- Very Good (2)
- Good (3)
- Fair (4)
- Poor (5)
- Don't know/unsure (6)

Q38 Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
- Number of days (out of 30): (1)
  - None (2)
  - Don't know/Unsure (3)

Q39 Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
- Number of days (out of 30): (1)
  - None (2)
  - Don't know/Unsure (3)

Q40 During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?
- Number of days (out of 30): (1)
  - None (2)
  - Don't know/Unsure (3)
**Sense of Virtual Community Scale**

The following questions will ask you about your attitudes about membership in online support groups. If you are not in any online support groups specifically for Sickle Cell Disease, please skip this portion of the survey. If so, please read the following questions and select your agreement with the statements. 1-Strongly disagree, 4-Strongly agree.

Q41 I think this group is a good place for me to be a member.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q42 Other members and I want the same thing from this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q43 I can recognize the names of most members in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q44 I feel at home in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q45 I care about what other group members think of my actions.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q46 If there is a problem in this group, there are members here who can solve it.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q47 It is very important to me to be a member of this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q48 I expect to stay in this group for a long time.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q49 I anticipate how some members will react to certain questions or issues in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q50 I get a lot out of being in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q51 I've had questions that have been answered by this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)
Q52 I’ve gotten support from this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q53 Some members of this group have friendships with each other.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q54 I have friends in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q55 Some members of this group can be counted on to help others.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q56 I feel obligated to help others in this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q57 I really like this group.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Q58 This group means a lot to me.
- Strongly disagree (1)
- Somewhat disagree (2)
- Somewhat agree (3)
- Strongly agree (4)

Sense of Community Index II

Please complete the following scale if you are a member of a face-to-face support group for Sickle Cell Disease. If you are not a member of a face-to-face support group, please skip the following questions.

Q59 How important is it to you to feel a sense of community with the other community (group) members?
- Prefer Not to be Part of This Community (1)
- Not important at All (2)
- Not Very important (3)
- Somewhat important (4)
- Important (5)
- Very Important (6)

Sense of Community Index II- Continued

How well does each of the following statements represent how you feel about this community (support group)?

Q60 I get important needs of mine met because I am part of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q61 Community members and I value the same things.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)
Q62 This community has been successful in getting the needs of its members met.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q63 Being a member of this community makes me feel good.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q64 When I have a problem, I can talk about it with members of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q65 People in this community have similar needs, priorities, and goals.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q66 I can trust people in this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q67 I can recognize most of the members of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q68 Most community members know me.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q69 This community has symbols and expressions of membership such as clothes, signs, art, architecture, logos, landmarks, and flags that people can recognize.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q70 I put a lot of time and effort into being part of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q71 Being a member of this community is a part of my identity.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q72 Fitting into this community is important to me.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q73 This community can influence other communities.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)
Q74 I care about what other community members think of me.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q75 I have influence over what this community is like.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q76 If there is a problem in this community, members can get it solved.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q77 This community has good leaders.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q78 It is very important to me to be a part of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q79 I am with other community members a lot and enjoy being with them.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q80 I expect to be a part of this community for a long time.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q81 Members of this community have shared important events together, such as holidays, celebrations, or disasters.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q82 I feel hopeful about the future of this community.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)

Q83 Members of this community care about each other.
- Not at All (1)
- Somewhat (2)
- Mostly (3)
- Completely (4)