EDUCATION AND SICKLE CELL ANEMIA: A NARRATIVE STUDY OF THE EDUCATIONAL EXPERIENCES OF INDIVIDUALS LIVING WITH SICKLE CELL ANEMIA

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Dedication

This doctoral thesis is dedicated to my father and mother, Professor (Dr.) Wande Abimbola and Mrs. Felicia Olanrewaju Abimbola (née Akanbi), for their boundless support, unremitting encouragement and love. They have constantly taught me invaluable and great examples, to work hard and pursue my goals in life, and to strengthen my dreams and aspirations to even greater heights in order to turn them into reality. My heart is overwhelmed with endless gratitude, and overflows with deep humility and happiness for their diligent effort and support.

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If the skies represent the beginning of the highest limit, then I am yearning with euphoric anticipation for the boundless expeditions that await me. My voyage abounds!
Abstract

This qualitative research is the first of its kind to proffer a comprehensive look into the educational experiences of individuals living with Sickle Cell Anemia (SCA). Social Disabilities Theory and Individual Resilience Theory were used as the two theoretical frameworks for this research. Four people were selected from all four regions of the United States. These individuals were selected to participate in this research through criterion and snowball sampling. Each participant completed a brief questionnaire that was used to facilitate a characterization and detailed description associated with each person. Each participated in two structured open-ended interviews that allowed them to narrate their own stories about their educational experiences as individuals living with SCA. Participants responded to a series of questions that focused on their life history, personal and educational experiences with SCA as well as, their past and present experiences with SCA. Study findings include themes and sub-themes: (1) SCA Pitfalls to Higher Education – SCA Interferes With Educational Experiences and Opportunities, The Journey to Higher Education, Balancing Academics and SCA, and Higher Education A Necessity; (2) Resiliency: Living Through SCA – Building Resilience to Cope with SCA, Family Support and SCA, and Spiritual-Religious Coping; (3) The Challenges of SCA – SCA and Stress, The Emotional Impact of SCA on Family, and A Burden Shared and A Journey Shared; and (4) Living with Uncertainties (SCA) – SCA and Social Life, A Secluded Life Echoes Solitude, and SCA and Quality of Life. Themes and sub-themes that were uncovered in the data are relevant to the realities of persons living with SCA. Findings provide valuable insight into the educational experience of these four individuals as they advanced to obtain a higher education. Keywords: Sickle cell anemia, sickle cell disease, educational experiences, higher education, pain crisis, stress, resilience, social disabilities theory, individual resilience theory, narrative
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Chapter 1: Introduction

Broad Overview of Research

Most children living with Sickle Cell Disease (SCD) will perform in academic work equally well as their non-disabled peers (Dyson, Atkin, Culley, Dyson, Hala & Rowley, 2010a; Routhieaux, Sarcone & Stegenga, 2005; Taras & Potts-Datema, 2005), but for some children with the disease, school has enormous implications on attendance (Schwartz, Radcliffe, & Barakat, 2009) which is directly related to academic performance (Nettles, 1994; Ogunfowora, Olanrewaju, Akenzua, 2001). Having a chronic illness such as SCD coupled with various factors associated with it at times may result in diminished and/or impaired academic performance (Ogunfowora et al., 2001; Schwartz et al., 2009). Rees, Williams and Gladwin (2010) wrote that, “a minority of people with the [sickle cell] disease has [sic] few complications and their disease is clinically unapparent, a majority has [sic] intermediate forms, and another minority has [sic] severe complications including cognitive and intellectual problems which appears in the developmental period” (p. 2022).

The severity of SCD and complications vary, therefore, given that the complications vary from person to person, some people who have the disease have long-term chronic pain while others may have less severe pain crisis (Rees et al., 2010; Ogunfowora et al., 2001). For some people, the disease can interfere with their everyday life and for some people; it can be a daily challenge throughout childhood to adulthood (Schwartz et al., 2009). Hence, improved access to better overall educational experiences and outcomes for people with the disease is a pivotal factor to the achievement of broader aspirations – including schooling experiences and attainment, career opportunities, work and personal life (Nettles, 1994; Ogunfowora et al., 2001; Schatz, Finke & Roberts, 2004; Schwartz et al., 2009). There are many different types of SCD.
SCD is the common name for a group of disorders. In order to avoid confusion due to the many different types of SCD, the focus of this research study is on Hemoglobin SS Disease – Sickle Cell Anemia (SCA), the most common type of SCD. The terms SCD and SCA will be used throughout the study as appropriate. This research has attempted to explore and describe the educational experiences of four people who have reached the age of twenty five or older living with Sickle Cell Anemia (SCA).

**Statement of the Problem**

SCD is a chronic, complicated and life-long genetic disorder that could impact learning and academic achievement of some of the people who suffer from this disease. SCD is the first recognized genetic disease in the world and one of the most prevalent genetic diseases in the United States (Centers for Disease Control and Prevention [CDC], 2010). SCD is a severe blood disorder that affects hemoglobin (disorder due to hemoglobin S), the protein in red blood cells to become disc shaped, doughnut shaped or shaped like a crescent in which the body then makes “sickled or “sickling” shaped red blood cells that carry oxygen from the heart to all parts of the body (CDC, 2010; National Heart, Lung, and Blood Institute-National Institute of Health [NHLBI-NIH], 2012). The severity, symptoms and signs of the disease vary vastly depending on the specific type of SCD. Some people have mild to moderate symptoms, while others may have acute to severe symptoms with frequent pain. They may sometimes need to be hospitalized for medical care and management in order to ease the symptoms. SCD can affect many parts of the body and can cause varied complications. Some of the most common complications include the following: (a) anemia, (b) pain, (c) acute chest syndrome, (d) pulmonary hypertension, (e) infections, (f) hand-foot syndrome, (g) iron overload, (h) ulcers on the legs, (i) avascular
necrosis, (j) silent stroke (ischemic stroke), (k) transient ischemic attack, (l) eye problems, (m) priapism, (n) gallstones, (o) multiple organ failure, (p) splenic sequestration (NHLBI-NIH, 2012). Other symptoms of the defective hemoglobin gene that are linked to the SCD complications may affect brain function in patients who have few or mild complications of the inherited blood disease (NHLBI-NIH, 2010). There is emerging data from researchers within the NHLBI-NIH supported Comprehensive Sickle Cell Centers that suggests that some patients of SCD may develop cognitive and intellectual problems at an early age, such as having difficulty organizing their thoughts, making decisions, short-term memory, processing speed, attention or learning, even if they do not exhibit severe signs and symptoms that are associated with the disease’s complications. It was furthermore noted that such adverse challenges can, indeed, result in poorer quality of life for those individuals affected by the disease.

Researchers have reported evidence that people affected with this disease can face intellectual and academic challenges (Dyson et al., 2010a; Routhieaux et al., 2005; Schatz, 2004, Taras & Potts-Datema, 2005). Existing research studies have shown that recurring sickle cell pain crisis can cause frequent hospitalizations and school absenteeism for some students with the disease (Barbarin, Whitten, Bond & Conner-Warren, 1999; Day & Chismark, 2006; Taras & Potts-Datema, 2005; Schatz, 2004). Taras and Potts-Datema (2005) conducted a longitudinal study that revealed evidence that SCA can affect student achievement and ability. The conclusion of this analysis is that there were significant amount of cognitive functioning deficits for some students with this disease.

Similarly, Routhieaux, Sarcone and Stegenga (2005) found in their study that it is clearly evident that some children with SCA show a decline in academic work. Routhieaux et al. (2005)
reported that the decline is the result of SCA neurocognitive deficits. Based on available studies, evidence suggests that schools should carefully deal with children with this condition with an understanding of the disease and its effect on students’ outlooks for the future (Daly, Kral & Brown, 2008; Day & Chismark, 2006; Schatz, 2004). Researchers furthermore suggest that educational interventions will improve the quality of students’ academic life and overall performance outcomes (Dyson et al., 2010a; King, Tang, Ferguson & DeBaun, 2005). Some researchers advise that schools should pay closer and special attention to the needs of students with the disease, particularly for those having any learning and academic difficulties (Routhieaux et al., 2005; Schatz, 2004; Taras & Potts-Datema, 2005).

Current and existing stories of persons with the SCA are largely missing from professional and scholarly literature, and may not be well understood. Today’s professional and scholarly research has largely focused on clinical and medical aspects of the disease such as, pain crisis and management, therapy to reduce the severity of the disease, pulmonary and acute complications, disability, blood transfusions, medical trials and experimental medications (Dyson et al., 2010a; 2010b; Rees et al., 2010; Ogunfowora et al., 2001). However, what is missing from the scholarly literature is a qualitative investigation of the stories and experiences of individuals who are adversely affected by the disease. Little research has been done that focuses specifically on the educational experiences of individuals living with the disease. The study of people with this disease is complex, yet relevant to the experiences of other individuals living with the disease; and to a wide range of persons with other chronic illnesses and disabilities in the American school system. Thus, this research sought to give a voice to individuals with SCA to have their opinions and feelings heard.
In the United States, the exact number of people living with SCD is unknown (CDC, 2011). However, the CDC estimated that there are 3 million Americans who have Sickle Cell Trait (SCT) and 90,000 to 100,000 have SCD (CDC, 2011). Currently, the CDC in collaboration with the NIH and 7 states are coordinating the Registry and Surveillance System for Hemoglobinopathies (RuSH) project to learn about the number of people living with SCD in the United States. Nigeria has the largest population of people with SCD in the world with around 150,000 babies born with the disease annually; this is about three-quarters of SCD births worldwide (CDC, 2012). With the increasing number of babies born around the world with SCD each year, it is important we learn as much as possible about how it affects those who suffer from it. Despite the fact that over 300,000 babies are born annually worldwide with this disease, and likely to reach epidemic proportions of over 500,000 babies by the year 2050 (CDC, 2011), the personal stories of persons living with this SCA is needed in order for us to gain greater understandings into the experiences that are unique to each person with SCA and shared by most people with SCA.

**Purpose Statement**

The purpose of this research was to explore and describe the educational experience and perceptions of individuals living with SCA; and to better understand the factors that are perceived to be the contributors and barriers to the advancement of a higher education for persons living with SCA. It is hoped that this research will represent a way to add to the literature, to the body of knowledge and awareness of this prevalent disease by the highlighted and shared stories of individuals who have lived through struggles and life challenges as they accept and overcome the challenges of living with a chronic long-term health condition.
Research Question

The central question that guided this narrative research study is:

What are the educational experiences of individuals living with SCA?

This question guided the exploration of the experiences of 3 to 4 individuals who are living with SCA.

Significance of the Problem

The purpose of this research was to explore and describe the educational experiences of individuals living with SCA. There are many children who are identified as having SCA (CDC, 2010; NHLBI-NIH, 2012). Yet, minimal research has been directed toward the increasingly growing number of people with SCA who show a decline in academic performance. Studies exploring the educational experiences of individuals diagnosed with SCA thus far have been inconsistent, their experiences are not well researched nor are they well understood. Ezenwosu, Emodi, Ikefuna, Chukwu and Osuorah (2013) conducted a study using examination reports of school-age children with SCA between the ages of 5 and 11 who had been in the same elementary school for over one academic school-year to investigate if there were some underlying factors which may have potential influence on their academic performance. The results of the study demonstrated that there are significant numbers of individuals with SCA and these individuals face many challenges. Schatz (2004) collected and analyzed significant amounts of data in South Carolina. Results from data collected suggest that approximately 30% of school-age children with severe SCA have difficulties either with performance levels in academic subject area or attainment i.e., math, science and language arts. Schatz (2004) concluded that academic achievement and attainment outcomes are at a rate statistically higher
for children with SCA when compared to children without SCA. The results suggest that the effects of SCD on school outcomes may be complex. Therefore, it is important to explore the educational experiences of individuals living with SCA. Thus, this research aimed to help us understand how some individuals living with this disease have managed to break through and progressed successfully through the American educational system, despite the many challenges they face on a daily basis.

Additional findings by Schatz (2004) suggest that approximately 25% of school-age children with SCA may have small brain injuries resulting from a silent stroke. Schatz (2004) emphasized that due to the fact that these small injuries do not lead to the visible signs of stroke, like a seizure or weakness in a limb, the injury goes unrecognized. More than likely, those children have difficulties with focusing, concentrating and sustaining attention during cognitive activities compared with their non-SCA peers (Schatz, 2004). Schatz (2004) indicate that other school related difficulties can be caused by a variety of complications due to the anemia itself. Such complications include pain crisis (long-term), fatigue (tiredness), fear, depression, anxiety and stress on bodily organs, which also can dramatically limit a child’s ability to concentrate the mind on tasks at school and pay attention in a classroom setting. This lack of focus and short attention span can impact a child’s potential to learn and achieve good grades. Daly, Kral and Brown (2008), Day and Chismark (2006), and Taras and Potts-Datema (2005) stated that the effects of SCA pain on academic achievement have yet to be extensively studied. These researchers suggest that, it is important for educators to be aware of the complex relationship between SCA and its effects on students’ education. The following paragraph describes the goals of this research.
Professional and Intellectual Goals

First and foremost, it is important to note that this research is not physiological, pharmacological or medical in the sense of relating to the treatment of the SCA. Rather, the research was designed to explore and describe the educational experiences of individuals living with SCA. The professional goals of this research were: (1) to explore and describe the educational experiences of individuals living with SCA; (2) to understand the challenges that persons with SCA are faced with on a continuing basis; and (3) to identify common themes and patterns within the participants’ description of their experiences. The intellectual goals of this research were: (1) to gain new insights and enhanced awareness of the experiences of persons with SCA; and (2) to use the researcher’s personal experiences, specific recollection and understanding as a SCA patient to provide another approach to address the topic.

Theoretical Framework

In order to understand the personal stories and experiences of persons with SCA, it was very important to bind the research by using identifiable theoretical frameworks. One of the underlying premises of theoretical framework(s) in qualitative research is that it facilitates and firmly grounds the development of research questions, guides the planning of data collection and helps to focus the structure of data analysis (Fowler, 2006). A theoretical framework can help a researcher to “easily distinguish relevant from irrelevant material” (Fowler, 2006, pp. 51-52), thus, “illuminates and conceals” (Fowler, 2006, p. 52) the set of data that is being collected. Fowler (2006) posits that researchers often find that no single theoretical framework adequately represents, explains or hold rigidly to any or all their research data. Fowler (2006) emphasized
further that “it is not uncommon for qualitative studies to be based on more than one theoretical framework” (p. 55).

With a better understanding of what theory is and the different ways in which it can be used in qualitative research, this project utilized two theoretical frameworks as lenses through which this research was viewed. Both theoretical frameworks were utilized to highlight the central findings, to describe and articulate the fundamental issues of the study; and to stimulate a better understanding of the investigation of the educational experiences of individuals with SCA. The theoretical frameworks are: Social Disabilities Theory (SDT) and Resilience Theory, specifically Individual Resilience Theory (IRT). The two theories complemented one another, and are not reducible to one theory. The insights they provoked were particularly and critically important to the topic because of the limited understanding of the challenges individuals with SCA face in their daily lives. Hence, both theories provided different lenses through which to interpret the research question, research problems, data collected and the delivery of the findings. The following sections will describe each theory and how they complement one another.

**Social Disabilities Theory (SDT).** SDT is about “why people behave, interact, and organize themselves in certain ways” (Oliver & Barnes, 1998, p. 1). SDT suggests that “individuals with impairments are not disabled by their impairments but by the barriers that exist in society which do not take into account their needs” (Oliver & Barnes, 1998). These barriers are divided into three categories: (1) Environmental barrier: the environment is largely designed by non-disabled people. Thus, the environment does not benefit people with disabilities; (2) Economic barrier: not providing enough of the same opportunities that are afforded to non-disabled people to people who have disabilities; and (3) Cultural barrier: disabled people are
viewed as not normal in the eyes of the society and thus, the society has a prejudistic mind in its natural process for humans and has negative shared attitudes towards people with disabilities (Oliver & Barnes, 1998). People with disabilities are not afforded the same environmental, economic and cultural opportunities in the society and in the schools as non-disabled people (Oliver & Barnes, 1998). Oliver and Barnes (1998) emphasized that it is precisely these areas that many societies need to work on to establish a culture of belonging for those with disabilities and impairments.

SDT helped to locate the experience of being disabled within the context of the social environment rather than the individual. It should be noted that SCA is broader than disability and medical interventions, therefore, barriers are not always impairment related. Through this theoretical lens, environmental, economic and cultural barriers are seen as including or excluding certain individuals (Oliver & Barnes, 1998). As a result of these disadvantages, many people with disabilities and impairments experience social exclusion, oppression, marginalization and stigmatization in different aspects of life (Oliver & Barnes, 1998). Oliver and Barnes (1998) assert that “prejudice and discrimination disable and restrict people's lives much more than impairments and disabilities do” (p. 1448). Thus, as long as disability or impairment is “assumed to be an individual matter of personal tragedy or heroic triumph over difficulty, disabled people are excluded from society” (p. 1448). The use of SDT helped to understand how persons with SCA have been able to cope with both the societal limitations and restrictions placed upon them.

**Resilience Theory.** Resilience Theory is described as the “process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances such as trauma, significant life stressors or serious health problems and being able to bounce back from
the difficult experience” (Masten, Best, & Garmezy, 1990, p. 426). The term resilience has been used to label three different types of phenomena. (1) Persons who have experienced traumatic life events but have been able to recover well; (2) Persons who belong to at-risk or high-risk groups, but who have more favorable outcomes than expected; and (3) Persons who show positive adaptation despite intense life stressors (Masten et al., 1990). Resilience Theory addresses the strengths that people have (innate) and/or have developed within them that have enabled them to triumph in the face of adversity (Masten et al., 1990).

**Individual Resilience Theory (IRT).** Masten and Osofsky (2010) wrote that studies with resilience focus typically aims to assess positive as well as negative patterns of adaptation after trauma, negative outcomes, disaster, hardship, adversity and setbacks. There are multiple theories of resilience. They include: (a) individual (Masten & Osofsky, 2010); (b) family (Walsh, 2008); (c) community (Ganor, 2003); (d) economic (Rose, 2007); (e) ecological and social systems (Adger, 2003); (f) community social resilience (Kofinas, 2003). The resilience theory adopted for this research focused on factors and/or conditions that determine individual resilience. Individual Resilience Theory (Masten & Osofsky, 2010) was used as a framework for this research. This theory focuses specifically on “factors and/or conditions that appear to promote or protect good functioning during crisis or recovery period” (Masten & Osofsky, 2010, p. 1034). IRT is described as the innate or learned characteristic that some people have to help them cope and/or deal better than others with life’s challenges (Masten & Osofsky, 2010). IRT is the ability of some individuals to effectively handle and cope successfully with intense life stressors despite having experienced traumatic life events (Masten & Osofsky, 2010).
IRT includes having the qualities of hardiness, self-efficacy, power and strength, endurance, resilient, optimism and determination. Therefore, IRT was an appropriate framework for conceptualizing the experiences of individuals who are faced with or have faced traumatic life events and how they adapt after the trauma (Masten & Osofsky, 2010). IRT is a useful lens for how resiliency can enable a person exposed to difficulty to withstand the adversity despite their disruptive experiences. IRT was a needed concept for this specific research because it complements the other theoretical framework discussed above. IRT supports the understanding of the structural barriers and the factors discussed in SDT that was used to explain the research findings.

**Summary of Theoretical Framework**

The selection of theoretical framework involves the specification of a theory or theories for carrying out an investigation on a particular topic. The two theories chosen for this research complement one another as there are certain barriers in life surrounding disabled and impaired people that hinder their daily lives and development. SDT examines these barriers while IRT challenges them; thereby, focusing on the ability to overcome them with a positive outcome. SDT examines environmental, economic and cultural influences and attitudes surrounding disabled and impaired persons in his or her environment, and how societies excludes these individuals from almost every aspect of daily life (Oliver & Barnes, 1998). IRT examines the characteristics and challenges internal to the individual and how individuals emerged from the personal challenges and/or circumstances with positive outcomes (Masten & Osofsky, 2010). The research sought to explore and describe the educational experiences of individuals living with SCA. Thus, this research focused at the complex issues surrounding those with SCA and
their educational journeys. In summary, these two theories were deemed appropriate for the purpose of this project and represented strong lenses through which this research explored the experiences of individuals living with SCA.

**Definition of Terms**

Definition of terms for this research is defined below (see Appendix A).

**Study Delimitations**

Participants in this research were limited to people who are diagnosed as having Sickle Cell Anemia (SCA). SCA is one of a group (a specific type and the most common, Hemoglobin SS disease) of inherited red blood cell disorders known as Sickle Cell Disease (SCD). All the participants in this research also have reached the age of 25 years or older, and have earned at least an associate, bachelor, master or doctorate degree. This research excluded all others who did not meet the criteria.

**Study Limitations**

The goal of this narrative research is to describe the educational experiences of individuals living with SCA. With true humbleness, this research has successfully accomplished that purpose with passion, depth and trustworthiness. With honest awareness, it should be noted however, that despite the significant contributions of this research, there were limitations that should be taken into account. Study participants were spread out over a wide geographic area of the United States; therefore, the interview process was conducted via telephone conference. This technique may have limited the personal communication that a face-to-face interaction may have offered. Thus, the nature of this communication limited the reading of body language, facial and emotional expressions.
One aforementioned limitation is that the researcher has personal feelings and emotions to the research topic as she is also a patient of SCA. This means that the researcher may have foregone conclusions which may have inadvertently influenced the research, and its findings. To counteract these personal perceptions, all interviews were audio-recorded and then transcribed verbatim. To further limit possible researcher bias, the transcripts were reviewed in their entirety several times, and coding was used to identify, organize and re-organize the data into meaningful patterns, categories, concepts and themes.

**Overview of Methodology**

This research focused on the educational experiences of individuals living with SCA. The research question for this study was: what are the educational experiences of individuals living with SCA? Qualitative research methods represented the best approach for carrying out this project. However, there are many techniques for carrying out qualitative research as well. The specific one that was employed for this research was a narrative approach. Given the fact that this project focused on individual stories told to the researcher, a narrative approach was best suited for this research. A narrative approach allowed the researcher to focus on elements generated from the data collected. This approach allowed for an exploration of different realities and meanings from the participants’ personal experiences and personal views. This research also employed social disabilities and individual resilience theoretical research perspectives as the two frameworks for the research design.

The qualitative nature of this research allowed the researcher to collect narrative data from 4 individuals who have reached the age 25 years or older, and with at least a bachelor’s degree. Open-ended interviews, review of documents and reflective memos were primarily the
three methods of data collection. Interviews were audio recorded, transcribed and coded. Data was inductively examined using categorical-content analysis methods of Lieblich, Tuval-Mashiach and Zilber, 1998. A detailed outline of the methodology was further discussed under research design and methodology in chapter three. The study’s definition of terms was defined in the appendices section (see Appendix A).

**Summary of Contents and Organization of the Study**

This doctoral thesis consists of the traditional five chapter organization. Chapter 1 presents a broad overview of research project, statement of the problem, purpose statement, research question, significance of the problem, professional and intellectual goals, theoretical frameworks, and overview of the methodology. This chapter also highlights some of the limitations and assumptions of the study. Chapter 2 provides an analysis of literature. This chapter is organized into four broad categories, which include an analysis of published information relevant to history and evolution of SCD, characteristics of SCA, medical, psychological, sociological and educational findings. A review of relevant literature in each of the four broad categories was critically analyzed to permit inclusion of only information which directly relates to the research. Furthermore, gaps in the existing literature were identified. This chapter also provided a rationale for SDT and IRT. Chapter 3 provides a detailed description of the research design and methodology that was used for this research. Chapter 4 provides the data analysis, summary of the research findings and discussions. Chapter 5 provides the summary, discussions, conclusions, implications and recommendations for future research.
Chapter 2: Literature Review

Introduction

It is important to acknowledge at the outset that even though research on SCA is ongoing and large, the body of research on the personal experiences of people with the disease is quite limited. This research was carried out to explore and describe the educational experiences of individuals living with SCA. This research therefore collected specific in-depth information from individuals living with the disease using three different kinds of data collection approaches for qualitative research: (1) open-ended interviews, (2) document reviews, and (3) reflective memos.

This chapter reviews, summarizes, and provides a background and presents an array of research that pertains to the research. Relevant sources, such as published literature from medical, psychological, sociological, educational and historical journals on issues relating to individuals with SCD were reviewed. This literature review also highlights gaps and insufficient information within current empirical research. Additionally, this chapter examined the literature with elements of two theoretical frameworks chosen for the study (social disabilities and individual resilience theories) to harness ways of thinking. The review began with an overview of the history, evolution and characteristics of SCD, followed by a discussion of the medical, psychological, sociological and educational findings.

Procedures for the Literature Review

The literature review began with a search of various combinations of the following strategic keywords, terms and phrases related to the topic: (a) Sickle Cell Anemia, (b) Sickle Cell Disease, (c) Sickle Cell Disorder, (d) Sickle Cell Disease Education, (e) Health Services, (f) Special Education, (g) Coping with Sickle Cell Anemia, (h) Cognitive Impairment, (i) Chronic Illness, (j) Other Health Impaired, (k) Individualized Education Plan, (l) 504 Plan, (m)
Absenteeism (n) Frequent Hospitalizations, (o) Educational Development, (p) Learning and Academic Achievement. These keywords, terms and phrases resulted in a total of thirty one articles relevant to this research. The various databases used in the search included:

- EBSCO Information Services (EBSCO HOST)
- Google Scholar
- The Educational Resources Information Center (ERIC)
- Education Research at Northeastern University Libraries
- OvidSilverPlatter Online Research Systems (OvidSP)
- Sickle Cell Information Center (SCINFO)
- Sickle Cell Foundation
- Sickle Cell Foundation of Georgia
- Children’s Sickle Cell Foundation

The combination of keywords, terms and phrases used above resulted in 26,035 articles using the EBSCO HOST database. When searching Google Scholar database, 37,500 articles were produced. ERIC database resulted in 97 articles. Education Research at Northeastern University Libraries generated 32,081 articles. OvidSP resulted in 4,970 articles. Sickle Cell Information Center resulted in 201 articles using some of the terms stated above. Sickle Cell Foundation, Sickle Cell Foundation of Georgia and Children’s Sickle Cell Foundation generated useful and valuable information for family support, education support and advocacy. Video clips, useful links, fund raising events and some newsletters on the topic were found, but there were no research articles or books. To ensure that more accurate and relevant articles were generated, the most utilized key words, terms and phrases on the topic were used. When searching the database
of EBSCO HOST, Google Scholar, ERIC and Northeastern University libraries, advanced search was selected and then checked for applied related words because of limited existing research on the topic. Finally, the search was narrowed down by selecting the box for source types, subjects, scholarly, peer reviewed and journals.

**History and Evolution of Sickle Cell Disease**

Sickle Cell Disease (SCD) also known as Sickle Cell Anemia (SCA or better known as Hemoglobin SS Disease or Drepanocytosis) is a group of genetic (inherited) disorders (conditions) that affect hemoglobin and causes the red blood cells to become sickle-shaped instead of a normal disc or doughnut shape (NHLBI-NIH, 2012). The term SCD and SCA are often used interchangeably. However, there are several conditions that are included as SCD with each one having a very specific different genetic makeup than the rest, but all identified as belonging to the broad group SCD. Examples are: Sickle Cell Trait (SCT), Sickle-Hemoglobin S (SS) or Sickle Cell Anemia (SCA), Sickle-Hemoglobin C Disease, Sickle-Hemoglobin D Disease, Sickle-Hemoglobin O Disease, Thalassemia, Beta-Thalassaemia, Beta-Plus Thalassemia, Beta-Zero Thalassemia, Alpha-Thalassemia, and Delta-Beta Thalassemia (NHLBI-NIH, 2012). SS or SCA is the most common of them all (NHLBI-NIH, 1996; 1999; 2010; 2012).

In 1978, Thomas Maniatis (b. 1943) an American professor of molecular and cellular biology isolated the gene for beta globin (Harvard University, Department of Molecular and Cellular Biology [MCB], 2012). Maniatis made ground-breaking contributions to the diagnosis and treatment of Thalassemia through the development of techniques that led to the cloning of the globin genes, specifically the hemoglobin gene (MCB, 2012). Maniatis pioneered molecular genetic studies for the prenatal and postnatal Deoxyribonucleic acid (DNA) based diagnosis of
In 1956, Vernon Martin Ingram (1924–2006) a German American professor of biology at the Massachusetts Institute of Technology (MIT) showed that SCD was due to replacement of an amino acid in the abnormal hemoglobin. Ingram (1956; 1957) was the first researcher to demonstrate for the first time that genes determine the nature of each amino acid in a protein and that a single amino acid exchange in a protein can cause a disease or disorder. Ingram (1956) determined that the change in the hemoglobin molecule in SCT and SCD was the substitution of the glutamic acid in position 6 of the β-chain of the normal protein by Valine (α-amino acid). Ingram (1956; 1957) used electrophoresis and chromatography to show that the amino acids of normal humans and SCD hemoglobins differed due to a single mutated gene. Ingram is referred to as “The father of Molecular Medicine” (MITnews, 2006, para. 1).

In 1949, James Van Gundia Neel (1915-2000) an American geneticist played a key role in the development of human genetics as a field of research in the United States. Neel studied SCD and showed that the transmission of SCD is Mendelian or Mendelian Inheritance - separate genes for separate traits are passed independently of one another from parents to offspring (The National Academies Press, 2000). In the same year, Linus Carl Pauling (1901-1994), Harvey Akio Itano (1920-2010), Seymour Jonathan Singer (b. 1924) and Ibert C. Wells (1921-2011) published a paper in the Journal of Science, “Sickle cell anemia a molecular disease.” A disease caused by the association of the disease with the alteration of hemoglobin, a molecule necessary for life. Pauling, Itano, Singer and Wells (1949) showed that the disease was due to an abnormal structure of hemoglobin. Pauling et al. (1949) demonstrated that the difference between
hemoglobin proteins taken from people with SCD is different from the hemoglobin of people without the disease using moving boundary electrophoresis. This showed that SCD is characterized by a lesser solubility than other forms of hemoglobin, i.e., insolubility of Sickle Hemoglobin (HbS). Pauling et al. (1949) discovered the molecular origin of a genetic disease.

This collection of clinical findings discussed above was unknown until James Bryan Herrick (1861-1954) a Chicago cardiologist and professor of medicine first explained and described SCD in 1910 as a genetic condition that results in a decrease in the ability of red blood cells to carry oxygen throughout the body. In 1904, James Herrick’s intern Ernest Edward Irons (1877-1959) found “peculiar elongated and sickle-shaped red blood corpuscles” (Herrick, 1910) in the blood of a 20 year old first-year dental student by the name Walter Clement Noel (1896-1916) from Grenada (a British crown colony from 1763 to 1974). Walter Noel was admitted as an inpatient to the Chicago Presbyterian Hospital for treatment, diagnosis and observation in December 1904. He was found to be suffering from severe anemia, muscular rheumatism, bilious attacks, fever and cough. Walter Noel also suffered from dizziness and headaches for a year coupled with palpitations (an unusually rapid beating of the heart) and shortness of breath (Herrick, 1910). The blood test showed that Walter Noel was very anemic, i.e., the number of red blood cells is less than half the normal value (Herrick, 1910). The observation of a blood film showed unusual shaped red blood cells (Herrick, 1910). The disease was later named “Sickle Cell Anemia” in 1922 by a well-known internist diagnostician, Verne Rheem Mason (1889-1965), who was a member of the medical faculty of the University of Southern California, a professor of clinical medicine, and an attending physician at Cedars of Lebanon Hospital (Mason, 1922).
Published reports of this condition were in African medical articles. A paper in African medical literature in the 1870s, reported this as a tropical and subtropical condition or disease locally known as “ogbanjes” (The Sickle Cell Association of New Jersey [SCANJ], (2009) or “abikus” because infant death was a common place (W. Abimbola, personal communication, December 31, 2013). The translation of the word “abikus” in Yoruba language of the Yoruba people, an ethnic group of West Africa is predestined to die (W. Abimbola, personal communication, January 12, 2014). The literal translation of the word “ogbanjes” in the Igbo language of the Igbo people, an ethnic group of southeastern Nigeria is “children who come and go.” (W. Abimbola, personal communication, January 12, 2014). Ogbanjes and Abikus refer to the spirit or spirits of children who die before reaching puberty or not passing puberty until death of the child (W. Abimbola, personal communication, January 12, 2014). The spirits of children are called ogbanjes and abikus because of the very high infant mortality rate within a certain amount of time from birth until their premature passing; it is believed that they come back again to repeat the cycle (W. Abimbola, personal communication, January 12, 2014).

Up until now, the Yoruba people of West Africa still believe in abiku (W. Abimbola, personal communication, January 12, 2014). They believe that a mother is troubled by abiku after she produces a child who died, produces another one who also dies and a third one who also died as well (W. Abimbola, personal communication, January 12, 2014). W. Abimbola says that these children are usually of the same sex (W. Abimbola, personal communication, January 12, 2014). We now know that SCD or SCA may be responsible for such premature mortalities, but the part that science may not be able to or as not addressed is why they must be of the same sex (W. Abimbola, personal communication, January 12, 2014).
The Yoruba people of West Africa for hundreds of generations because of high mortality rates in infants probably due to SCA at that time had come to believe that children that died prematurely were born and they had to repeat a cycle. This is how they best rationalized what was happening. In the 1870s, learned professional scientists were recognizing the high infants’ mortality rates among the blacks in West Africa. They were calling the cause a tropical disease, whereas the inhabitants were calling it ogbanje or abiku (probably SCA) not a tropical and subtropical condition or disease.

In 1846 the first medical report paper that best described the condition or the disease was found in the Southern Journal of Medical Pharmacology entitled “Case of Absence of the Spleen” by an American doctor R. Lebby (Innvista, 1997; Lebby, 1846; Konotey-Ahulu, 1973). Lebby looked at the organs in African Americans slaves who have died and discovered the absence of the spleen after the execution and an autopsy was performed on the body of a runaway slave in which the medical examination of the dead body established that this man having lived without a spleen (Innvista, 1997; Lebby, 1846; Konotey-Ahulu, 1973). Science has since proven that SCD will in certain conditions destroy the spleen (Desai & Hiren Dhanani, 2004; SCANJ, 2009). Investigators have tracked reports of the history of what is now called SCD back to a Ghanaian family to 1670 (Desai & Hiren Dhanani, 2004; Konotey-Ahulu, 1973, SCANJ, 2009).

Researchers determined that the origin of the mutation that gave birth to the SCD gene (the 11th chromosome) originated in the Arabian Peninsula, spreading to Asia and Africa (Lehmann, 1964). Four independent mutational events were identified, three in Africa, one in India or Saudi Arabia ((Lehmann, 1964). These independent events were estimated to have
occurred 3,000 to 6,000 generations ago, about 70,000 to 150,000 years ago before the development of the early civilizations (Lehmann, 1964).

**Characteristics of Sickle Cell Anemia**

The hallmark of SCA is the sickle cell crisis (also sometimes known as a vaso-occlusive crisis), which is an episode of pain. This episode of pain is the most common reason for hospitalization for sickle cell anemia patients. The sickled cells become hard and irregularly shaped resembling a sickle (Journal of the American Medical Association [JAMA], 1999). These sickled cells become clogged in the small blood vessels and therefore, do not deliver enough oxygen to the body tissues (JAMA, 1999). This lack of tissue oxygenation can cause excruciating pain, damage to body organs, and, if prompt medical attention is not received, this can cause death.

SCA is a congenital hemolytic inherited hemoglobinopathy that occurs predominantly but not exclusively among individuals of African descent, people whose ancestors originate from Africa (JAMA, 1999; NHLBI-NIH, 1996, 2011). It is also found in persons from Asia, Middle East, India, Cuba, Saudi Arabia, Turkey, Greece, Italy and Southern European countries, as well as in people of African ancestry who live in North, Central and South America (JAMA, 1999; NHLBI-NIH, 1996, 2011). SCA occurs more commonly among people whose ancestors lived in tropical and sub-tropical regions of African and the Caribbean, Indian and the Middle Eastern, and the Mediterranean regions where malaria is and was a common phenomenon (NHLBI-NIH, 2011).

SCA is not easy to endure and patients must constantly seek help and support from family, friends and medical care from hospitals. People with SCA sometimes require emergency care because “some of the hemoglobin forms long, rod-like structures that cause the red blood
cells to be sickle-shaped and stiff” (JAMA, 1999, p. 1768). These sickle-shaped cells block can clog small blood vessels, thereby “preventing some organs or tissues from receiving enough oxygen” (JAMA, 1999, p. 1768). These blockages can cause “episodes of severe pain or damage to organs and tissues” (JAMA, 1999, p. 1768), and may lead to other serious health problems and may even cause death. Sometimes the blockage and pain are so severe that these can cause pain in bones, muscles or abdomen, fatigue, paleness, jaundice, shortness of breath, stroke, swelling of the hands and feet, with stiff painful joints and extreme tiredness, vision problems or blindness (JAMA, 1999). At times, when it is too painful to walk, people might have to carry SCA patients, who are incapacitated by their pain, and indeed some patients have to use crutches during SCA pain episodes; such episodes of excruciating pain are called “painful crisis” (JAMA, 1999, p. 1768).

In the United States, 1 in 10 black newborns have Sickle Cell Trait (SCT) and 1 in 400 black newborns have SCA. 1 in 172 Latino newborns have SCT and 1 in every 1,000 to 1,400 Latino newborns have SCA (CDC, 2011). SCA is the most common inherited hemoglobinopathy blood disorder in the United States currently affecting approximately 90,000 to 100,000 people (CDC, 2011). The CDC (2011) estimates that there are approximately 300 million people with SCT worldwide, and at least 70 million people affected with SCD in the world. A normal hemoglobin gene is symbolized with the letter A and S to represent sickle hemoglobin genes. People who have two A genes are described as AA. Those who inherit one A gene and one S gene (i.e. those with AS genes) are described as having the disease trait SCT. People with SCT usually do not normally have any of the symptoms or complications of SCD because SCT is not considered as a disease. However, people with SCT can pass the trait on to their children. People
who inherit one S gene and another S gene (described as SS) from both parents get the condition called SCA or SS (NHLBI-NIH, 1996). The following sections are the literature that was reviewed about medical, psychological, sociological and educational findings of SCD and SCA.

**Medical, Psychological and Sociological Findings**

Barbarin, Whitten, Bond and Conner-Warren (1999) conducted a study on psychological assessment through a structured interview with patients living with SCD and their families and/or guardians to determine the psychological effects that SCD causes. The study was carried out by asking both open and closed-ended questions such as: patients and families educated knowledge of SCD; problems experienced by the families; information on financial needs and resources; impact of the illness on the immediate family, etc. These led to the formatting of quantitative indexes used as analysis to give a very descriptive review of the study. Barbarin et al. (1999) concluded that in order to cope well with the task of a chronic illness such SCD, the family must develop and sustain a routine around medical care. Barbarin et al. (1999) also stated that the family must also solve problems relating to the person with SCD’s limited stamina or other restrictions imposed by the illness. Pain episodes of the person with SCD disrupt and interfere with parents’ employment, and may threaten the family’s financial stability. Barbarin et al. (1999) revealed that the most difficult coping task for family members is managing their own emotional responses and anxiety when the person is in pain. Barbarin et al. (1999) concluded that family members should respond to these types of stressful situations by developing individual and family coping styles that is supportive of the person with SCD and his or her siblings.

Olley, Brieger and Olley (1997) conducted interviews and surveys at clinics in both public and private hospitals in Ibadan-Ibarapa Health Zone of Oyo State, Nigeria where a sample of 200 mothers of children with SCD were asked to talk about stressful situations in the
management of their children with SCD, as well as their coping mechanisms for their stressors. The study looked at stress factors listed by the mothers’ own experiences shared in focus groups discussions that preceded the survey. Stress levels were measured using a Likert-type scale. The analysis yielded six categories of stress situations: hospital, disease, financial, familial, psychological, and child factors. Olley et al. (1997) concluded that home expense, treatment cost, transportation, and providing the child with SCD a good and nutritional diet cause’s financial stress for the mother in the household. For instance, the family would try to secure money from relatives, borrow from other sources, try to earn the money, selling home goods in order to cover the cost of hospitalizations and so forth which causes more stress to the family.

The findings of the study revealed that 21 of the 200 women surveyed were single, which resulted in a lack of funds and social support from a husband and his relatives. This lack of family unit caused undue hardship and less certain financial status as the single mother could not take care of the SCD child and work simultaneously. Olley et al. (1997) determined that financial concerns were one of the top four factors of the six categories of stressors among mothers of children living with SCD. It was also established by Reynolds, Gerralda, Jameson and Postlethwait (1988) that financial, disease and disability factors are the major sources of stress among mothers of chronically ill and handicapped children. Olley et al. (1997) suggested that mothers of children with SCD may have a much better access and a greater understanding of the condition if they were higher educated, not only in the SCD category, but how to better care for the child. Also with the higher education, mothers will be able to procure higher paying employment and greater access to financial resources, which in turn will help to confront the source of the financial stress that she is under and less stress for the SCD child.
A structured questionnaire on health, well-being and psychosocial impact of carers of 67 children with SCA was conducted by Brown, Okereke, Lagunju, Orimadegun, Ohaeri and Akinyinka (2010) on how it impacted the carers of SCA children. Brown et al. (2010) collected data analysis using the Statistical Package for Social Sciences (SPSS) version 15.0. There was a significant correlation between financial stress and difficulty in parental coping. It was found that hospitalizations two or more times in a year would place financial stress on families of children with SCA especially if the family unit consisted of three or more children. Brown et al. (2010) examined other adverse effects on the family: financial loss, impairment of work efficiency, disruption of routine family activities including household work and attention to other family members.

The findings revealed that one of the financial losses occurs when the parent loses income because of loss of work while caring for the SCA child. The impact on family finances is also caused by time spent caring for the SCA child causing the mother to be away from the other minor children and having to secure a person to watch over, feed and transport the other children in the family. Brown et al. (2010) found that 58% of the families interviewed claimed they had been adversely affected financially because of their loved one having SCA; 13% of the families found it necessary to take out a loan to cover their child’s illnesses; 6% of these families expressed that the loan needed were so large that they found it difficult to pay it back. This study showed that financial distress and disease-related stressors can destabilize the coping ability of the carers. Brown et al. (2010) concluded that managing a child with SCA can cause financial distress and hardship for the family. It was suggested by Brown et al. (2010) that a good support system for family members as well as explaining the importance of higher education can
improve socioeconomic status and could help to relieve the financial and emotional burdens of the carers.

A cross-sectional study by Panepinto, Pajewski, Foerster, Sabnis and Hoffmann (2008) was conducted at the Children’s Hospital of Wisconsin/Medical College of Wisconsin to determine the impact of family income and SCD on the health-related quality of life (HRQL) of children between the ages of 2 through 18 with and also without SCD. A sample of 104 parents and primary caregivers of the children with SCD and 74 parents of children without SCD were asked to provide their total household income. 41 parents and primary caregivers of children with SCD refused to provide their income. 20 parents of children without SCD refused to participate due to lack of interest or not having time for the study. Panepinto et al. (2008) covariates of interest were family income, disease severity, other chronic conditions and age of the children. Family income was categorized into three groups of parents with income less than $20,000, $20,000 to $40,000 and greater than $40,000 based on work done in a prior evaluation of HRQL and income in 2006. Disease severity was classified into two categories, mild or severe disease regardless of the child’s SCD type. Other chronic conditions such as, asthma, chronic orthopedic/bone/joint problems, chronic rheumatic disease, diabetes and other chronic conditions were used to determine some of the other underlining causes of financial loss of income in addition to the SCD. Age of the children was examined using age categories of Pediatric Quality of Life questionnaire (PedsQL): 2-4 years, 5-7 years, 8-12 years, and 13-18 years. Descriptive statistics were used to compare the distribution of demographic factors between children with and without SCD because 41 respondents declined to give their income. Therefore, a census block group utilizing street addresses was used as a proxy to determine their income level. This
census block group was identified using the 2000 Census Summary File 3 from the U.S. Census Bureau’s American Fact Finder.

The results of the study revealed among other factors, the majority of parents in both groups were African Americans, although the parents of children with SCD were more likely to be African Americans compared to the parents of children without SCD. Children with SCD had the following types: 66 children with hemoglobin SS (SCA), 26 hemoglobin SC (Hemoglobin C Disease), 9 Hemoglobin SB+ (Beta-Plus Thalassemia), 1 Hemoglobin SB0 (Beta-Zero Thalassemia), and 2 other SCD variants. It was determined by Panepinto et al. (2008) that children with SCD have worse HRQL than children without SCD even after accounting for the potential detrimental effect of lower family income on HRQL when compared to families of children without SCD. Panepinto et al. (2008) concluded that children with SCD have worse HRQL when compared to children without SCD after adjusting for income levels and other significant covariates. Panepinto et al. (2008) also concluded that older children with severe SCD who have the lowest family income and co-morbidities have the worse HRQL. The study interestingly showed that parents of children without SCD had the lowest family income, while the parents of children with SCD had the higher percentage of family income, but their HRQL was considerably demised.

Nelson and Hackman (2013) conducted a confidential survey to all patients of SCD and their families at a Sickle Cell Clinic to address the issues of race and health care. The survey was accessible online to all staff in the hematology/oncology program of the hospital where the clinic was located. The purpose of the survey was to identify perceptions of race and racism among both staff and patients/families with particular attention to provider attitudes as a potential
contributor to racial healthcare disparities. The majority of patients/families (92.6%) were identified as black, while 94.1% of staff were identified as white. Survey was completed by staff members with an 85% return rate (135 out of 158 staff members). The researchers noted that most patients/families felt that race affects the quality of healthcare for SCD patients. The researchers reported that many factors affect healthcare equality and disparities because of race in the management of many diseases. For example, black people receive a lower standard of care than white people when being treated for breast cancer, orthopedic problems, cardiovascular disease, pain, and end of life care among others. In addition, being uninsured was the single strongest predictor of quality of care. Nevertheless, it was noted that when adjusting for uninsurance and socio-economic status, blacks still receive worse care than whites. Significant gaps exist in the treatment of blacks versus whites in the United States. For example, 90% of Cystic Fibrosis patients are white; however, they receive eight times more support than people with SCD which are predominantly black with 98%. Nelson and Hackman (2013) survey was conducted in Minnesota where 85.3% of the population is white and only 5.2% are black. Whereas in the United States, the general population is 72.4% white and 12.6% are black. Furthermore, 88.1% of physicians in Minnesota are white, while only 2% are black. In the United States in general, 75% of physicians are white and 6.3% are black.

Within the healthcare delivery, more patients/families felt that race affects the quality of healthcare for SCD patients and most staff perceived unequal treatment of patients. Although, within this survey most staff and patients/families agree that racism is a problem in the United States. Race affects healthcare delivery and is an important factor in healthcare disparities, but physicians often fail to see this. Nelson and Hackman (2013) examined other surveys; these
surveys show that 29% of physicians felt that the healthcare system treat people unfairly based on race, while 47% of the public felt this way. Only 4% of white physicians felt that healthcare systems treat people unfairly based on race, while 41% of black physicians felt this way. Nelson and Hackman (2013) stated that health care provider attitudes must change in order to help improve racial health care disparities. Nelson and Hackman (2013) concluded with a proposal that will train health care providers on issues of race, racial bias, racism, the role of racism in evidence-based medical protocols, and the realities of systemic racism and its impact on patients. Nelson and Hackman (2013) also concluded that training should be offered to the medical provider in order to teach them to care for patients with comfort and skill who are of a different race than their own. Nelson and Hackman (2013) intend to evaluate the effectiveness of the training module through pre- and post-surveys of participants. Nelson and Hackman (2013) stated that if the training they implemented is effective, they would advocate for widespread training of health care providers including early training in medical and nursing schools.

Haywood, Tanabe, Naik, Beach and Lanzkron (2013) conducted a cross-sectional, comparative analysis of year 2003 through 2008 data from the National Hospital Ambulatory Medical Care Survey, a nationally representative sample of nonfederal emergency department visits in the United States. The survey was used to determine the wait time (in minutes) to see a physician after arriving at the emergency department (ED) and was implemented using a generalized linear model to examine ratios of wait times. This model was used to determine whether SCD patients experienced longer wait time in ED compared to General Patient Sampling or patients with long bone fractures (LBF). The results of the study showed that SCD patients were more likely than the General Patients Sample or the LBF patients to be represented
in the higher priority triage group. Even though, Haywood et al. (2013) noted that SCD patients were given a higher priority triage number, they were seen by physicians in the ED significantly slower than the General Patients Sample or the patients with LBF. The average wait time for SCD patients was 66.8 minutes compared 44 minutes for the LBF patients. The difference between the two groups was 24.7 minutes. Longer ED wait times were reserved for patients with SCD compared to General Patients Sampling with a wait time of 53.6 minutes compared to SCD patients with a wait time of 13.1 minutes longer on average to see physicians in the ED.

Haywood et al. (2013) concluded that without adjusting for hospital characteristics, SCD patients wait approximately 25 minutes longer to see physicians in the ED compared to the General Patients Sampling, longer to see physicians than did the LBF patients. Even though, the SCD patients exemplified higher levels of pain and tended to be assigned higher priority triage ratings, they still had significant longer wait times.

The findings of Haywood et al. (2013) are consistent with other research that has found that African- Americans and other minorities experience lower quality pain management or longer delays than white patients upon arriving to an ED. For example, it was noted that black stroke patients had longer wait times to be seen and evaluated by an ED physician than did white stroke patients even after accounting for a higher assigned triage priority. In one of the conclusions, it was noted that SCD patients wait 50% longer to be seen by a physician in the ED compared to LBF patients. Although Haywood et al. (2013) explained that there are no doubt a number of circumstances that would be beneficial to see LBF patients ahead of some patients with SCD; it seems to suggest a more troubling conclusion that SCD status itself plays a role in the difference in waiting times. Haywood et al. (2013) confirmed that patient anecdotal report is
in need of intervention and updating. Thus, it was suggested that a closer re-examination of the way SCD patients are evaluated upon their arrival in the ED facility is necessary in order to provide the most efficient and highest quality of health care. A re-examination of the ways in which acute care is provided could lessen the disparity in the provision of quality emergency department care.

Telfair and Gardner (2000) researched the role of support groups on developmental, psychological and social issues common to patients with SCD. Telfair and Gardner (2000) described that support groups can help people with SCD in coping with emotional issues, anxiety, depression and stress. The findings suggest that support groups are generally considered valuable to people with chronic diseases such as SCD. Telfair and Gardner (2000) stated that support groups can enhance a feeling of empowerment and facilitate the giving and receiving of support. Telfair and Gardner (2000) concluded that support groups play an effective overall role in the well-being of people with SCD.

In contrast, Burley, Telfair, Colangelo and Wright (2000) examined whether psychological factors play a more important role than biomedical risk factors in predicting adaptation of individuals to SCD. Burley et al. (2000) also researched whether psychological factors moderate the relationship between biomedical risk factors and adaptation. The findings revealed that self-esteem, social assertiveness, stress-processing and social ecological factors were significant predictors of adaptation. Therefore, the conclusion of study shows that there is no evidence of psychosocial factors that moderated the relationship between biomedical risk factors and adaptation. There is a need for additional research to understand the nature of the interrelationship among biomedical risk factors, psychosocial factors and adaptation.
Gil, Porter, Ready, Workman, Sedway and Anthony (2000) examined the role of stress and mood in the onset and course of severe pain in SCD patients. A diary of events about pain, stress, mood and health medication used for an average of 94 days was examined. The study found that painful episodes were preceded by increases in stress 2 days before an episode of pain. This study provides an empirical data on the role of stress as a trigger for sickle cell pain. Since it has been verified by Gil et al. (2000) that stress and mood can cause painful episodes, it is important to have another research that examines the strenuous activities that may also cause a sickle cell pain outbreak in SCD patients.

Armstrong, Thompson Wang, Zimmerman, Pegelow, Miller, Moser, Bello, Hurtig and Vass (1996) conducted a particular study on cognitive functioning and brain magnetic resonance imaging that collected data through a cross-sectional studies approach of students with SCD. This research was carried out by comparing brain scans, child behavior surveys, and the results of neurological tests of intelligence (WJ-R Woodcock-Johnson-Revised and WISC-R Wechsler Intelligence Scale for Children-Revised) reading and math ability, and motor skills among students with SCD. This study revealed that development of a battery of screening tests that include evaluation of processing speed, visual-motor skills, arithmetic, memory and attention-concentration skills could provide early identification of Neuropsychological (NP) impairment. Armstrong et al. (1996) found that such testing could provide school personnel with information about specific abnormalities and allow the creation of focused educational plans to maximize a student’s performance. The major area of concern that was not addressed in this study is related to the Neuropsychological (NP) impairment evaluation, because both structural and functional
assessments of students with SCD are critical in the development of an appropriate education plan.

Schatz, Finke and Roberts (2004) examined whether biomedical risk factors and socioeconomic disadvantage factors play a more important role than cognitive functioning among students with SCD. In this study, anemia severity was a strong predictor of cognitive functioning among students with SCD. Schatz et al. (2004) suggests that students with SCD have particular difficulties in the area of crystallized intelligence, processing speed and short-term memory. The primary finding is that the level of anemia severity in SCD and social and environmental risk may not be simply independent factors, but interdependent factors for cognitive development. Schatz et al. (2004) concluded that the use of a comprehensive study approach may be of particular use because it provides a common framework for understanding which cognitive functions are being assessed across a range of different commonly used instruments (e.g., WISC-R, WJ-R and Kaufman assessment batteries). A more detailed level of understanding would be necessary to establish why some patients of SCA excel in academic studies while others do not. This could be critical for developing cognitive remediation strategies for the students already showing signs of cognitive deficits because of the disease. Other variables that could not be addressed by Schatz et al. (2004) are close ties with family or family support, better educational opportunities and financial well-being.

Taras and Potts-Datema (2005) conducted an experimental study which dealt with cognitive ability, school attendance and achievement of students with SCA. The study revealed evidence that SCA affects student achievement and ability. Taras and Potts-Datema (2005) found that the most significant neurocognitive impairments are in language and verbal abilities, visual
motor and visual spatial processing, processing of subtle prosodic, attention and memory. Taras and Potts-Datema (2005) recommends that schools should pay special attention to the needs of students with this diagnosis, particularly for those having any academic difficulties. Taras and Potts-Datema (2005) concluded that the effects of pain on school attendance and achievement of students with SCD have yet to be extensively studied. Taras and Potts-Datema (2005) advise health practitioners, teachers and educators to be updated on what is already known about this complex relationship between chronic diseases and their effects on students’ education.

Routhieaux, Sarcone and Stegenga (2005) document Cerebral Vascular Accident (CVA) or stroke has one of the major complications of hemoglobin SS (Hgn SS or SCA) disease. CVA has implications for physical as well as neurocognitive functions for children. Routhieaux et al. (2005) found that it is clearly evident that some students with SCA show neurological deficits in academic performance, brought on by SCA overt CVA or stroke. In the study, it was identified that arithmetic, reading skills, sustained attention, visual motor speed or coordination may be a problem for students who have experienced a CVA. Routhieaux et al. (2005) suggest that for students who have been identified to have neurocognitive deficits related to SCA, schools should have school-based services implemented as soon as possible. This knowledge, in addition to the student’s specific test results, could be instrumental in establishing specific individualized school programs based on Routhieaux et al. (2005) research findings.

Steen, Miles, Helton, Strawn, Wang, Xiong and Mulhern (2003) used a cohort method of research to study students with hemoglobin SC SCD. These students are known to suffer cognitive impairment if they have silent brain (cerebral) infarcts. Steen et al. (2003) stated that evidence suggests that students with hemoglobin SC SCD may be impaired even if they are free
of infarctions. Steen et al. (2003) tested a hypothesis that cognitive impairment in students with SC SCD is associated with low hematocrit and brain magnetic resonance (MR) imaging abnormalities. The result of the study showed that students with imaging abnormalities had more cognitive impairment than did students with normal imaging in verbal intelligence and verbal comprehension. Steen et al. (2003) also found that impairment is multifactorial and that chronic brain hypoxia is a part of the pathophysiology of SCD. The findings also indicate that it is time to consider clinical trials of interventions to increase hematocrit, with the goal of preserving cognitive function. Thus, the comparison between verbal intelligence, verbal comprehension and mathematical abilities, mathematical comprehension should be compared to determine if the damage to the brain is left hemispherical or right hemispherical, if so, will different method of teaching be advantageous for students with SC SCD.

**Educational Findings**

Ogunfowora, Olanrewaju and Akenzua (2005) conducted a comparative study to show a comparison between ages 6 to 17 years students with SCA and their siblings. Ogunfowora et al. (2005) evaluated percentage scores and the rate of students that passed in four subjects: Mathematics, English Language, Integrated Science and Social Studies. Ogunfowora et al. (2005) also evaluated the total number of school absenteeism for students with SCA and their siblings of similar socio-demographic characteristics, over one academic session. Ogunfowora et al. (2005) discovered that school absenteeism among students with SCA was significantly higher than that of their siblings. There were significantly larger proportions of below-average grades among students with SCA. The mean percentage scores of school absenteeism among the students with SCA compared well with those of their siblings. There was no significant
correlation between school absenteeism and academic achievement of the studied population. Ogunfowora et al. (2005) concluded that more children with SCA are underachievers in this study, and their school underachievement is not associated with the observed higher school absenteeism. The researchers suggest that it is necessary to pay close attention to the school performance of students with SCA, with a view of identifying early the academic achievement among students with the disease who may need help in the form of extra coaching and/or home lessons. For this reason, two separate studies are therefore needed in order to obtain fair and valid research findings for childhood diseases that are prevalent in many 6 to 12 year olds (mumps, measles, rubella, chicken pox, etc.) which are not prevalent in students ages 12 to 17.

King, Tang, Ferguson and DeBaun (2005) evaluated the effectiveness of a SCD education program from teachers of students with the disease in their classrooms. King et al. (2005) contacted 81 teachers, K to 12 in 10 schools with students in a remediation program for students participated in an educational program consisting of four domains: Inheritance and Prevalence, Common Complications, Strokes, and Individual Education Plans (IEP) with a pretest and posttest. The primary findings of the pretest and posttest showed that teachers’ knowledge of SCD improved significantly after the program intervention. However, results also suggest that teachers were not knowledgeable about the inheritance of SCD. For instance, how it affects students in the classroom. The major area of concern that could be addressed in the research is related to the absence of teacher knowledge and awareness about SCD and how it affects students in the classroom.

Dyson, Atkin, Culley, Dyson, Hala and Rowley (2010a) conducted a mixed methods based on 569 questionnaires and 40 taped interviews with young people living with SCD in
England. This research examined the patterns of disclosure, students’ failure to report their SCD in relation to reported school experiences. The aim of the research was also to interpret possible reasons why students are reluctant to disclosure the fact that they have SCD to teachers and their peers. The primary finding from this research is that students with SCD are faced with difficult problem whether to disclose their SCD to teachers or their peers or not. Dyson et al. (2010a) concluded that students with SCD refrain from explaining to anyone that they have the disease. Having interviewed many students, Dyson et al. (2010a) found that many students feel embarrassed, stigmatized, ostracized, and unequal and because of these facts, they seem to have fewer friends, basically loners and many drop out of school and do not continue with their education. Dyson et al. (2010a) also found that students with SCD were being treated unfairly as teachers and peers believed they were lazy when they get constantly tired or seem to think they are being anti-social for not participating in social situations and events. Dyson et al. (2010a) concluded that students who have disclosed to their teachers and peers that they have SCD have not received any better treatment than they had before it was disclosed. Dyson et al. (2010a) advised that changing the social and physical environment of the school is necessary so that young people with SCD feel supported whether they choose to identify themselves with the disease or not.

Dyson, Hala, Atkin, Culley, Dyson and Rowley (2010b) conducted a survey on school experiences and absences of young people with sickle cell disorder in England. The survey was conducted on a sample of 569 young people. The primary finding indicates that 1 in 8 student with the SCD in England have persistent school absences. Students who have been absent reported that they are not helped to catch up and make up these absent days. Half of them
reported not being allowed to drink water in class or to use the necessary bathroom breaks when needed. A third of the students reported being made to take Physical Education (PE) exercise and being called lazy when tired. Some students perceived both the physical environment (temperature control and furniture) and the social environment (being upset by teachers or other students) as triggers to episodes of pain crisis. Dyson et al. (2010b) concluded that current guidance on the management of young people with chronic illness such as SCD seems to fall short in a number of important ways. Dyson et al. (2010b) suggests that attending to the physical and social needs of young people with SCD is an important part of helping them achieve academic success. It is the researcher’s beliefs that the development of an education program for children with SCD will help maximize their full academic and social potential.

Similarly, Dyson, Atkin, Culley, Dyson and Evans (2011) conducted a field research using a multi-method study to examine the experiences of 40 young people with SCD in schools in England. The researchers conducted a thematic analysis utilizing Pierre Bourdieu’s concept of field, capital and habitus. The primary findings of the research indicate that young people with SCD are faced with many challenges. These challenges are usually and consistently dys-positioned between the health care maintenance, the school and academic demands which make social life difficult. Dyson et al. (2011) also found that the tactics of the students with SCD are framed by many social struggles and school activities which do not address aspects of SCD students in isolation. Teachers and peers’ reactions to SCD have “the enduring potential to drain the somatic, cultural and social capital” (Dyson et al., 2011, p. 465) of the students with the disease. Dyson et al. (2011) concluded that young people with SCD struggle constantly to find the right balance on their somatic, cultural and social lives. A similar field research is needed to
find out from young students and their parents how schools could address some of their concerns relating to SCD.

Noll, Vannatta, Koontz, Kalinyak, Bukowski and Davies (1996) conducted a research study to compare the social functioning of students with SCD to a comparison of peers, same age, race, gender and classroom with one-to-one matching. The results of the study revealed that female students with SCD were perceived by peers as being less sociable and less well accepted. While male students with SCD were perceived by peers to avoid circumstances with peers that could result in physical confrontations. For both male and female students with SCD, no other differences were identified on various measures of emotional well-being. Noll et al. (1996) conclude that none of the various measures of illness severity were significantly related to measures of psychological adjustment. However, the common side effects for male students with SCD are chronic fatigue and small physical size. For females, the common side effects may delay the development of normal social relationships. The study confirmed that students with SCD have restrictions on their physical activities and that they experience fatigue and tiredness more often than peers. This study also revealed that SCD has a significant impact on social and recreational functioning of students with SCD. Evidence from this research suggests that SCD affects students’ feelings about themselves. A limitation of this research is the lack of data as to whether or not the participants received extra scholastic help. Further research is needed to determine if a special educational support system could help improve students’ educational, social and life quality.

Noll, Reiter-Purtill, Vannatta, Gerhardt and Short (2007) conducted a controlled replication study of students with SCD using data collected as a part of a larger group in a
longitudinal study to find out the social and emotional functioning of students with SCD. Noll et al. (2007) examined the adjustment of children with SCD who like peers have not had the misfortune to have had overt stroke. Comparison peers described children with SCD as having fewer friends, less athletic, less energetic, sick more often and absent from school more frequently. The primary findings of the Noll et al. (2007) longitudinal study suggest relative psychological hardiness among students with SCD who have not had overt stroke. This research study was conducted by Noll et al. (2007) to simplify how children with SCD can cope with feeling of inadequacy and isolation to overcome their shortcomings and be accepted by peers. A social disabilities lens could have been used to show how schools could help children with SCD who may have feelings of inadequacy and isolation to overcome their shortcomings. In doing so, children who experience these feelings hopefully will be accepted by peers and their scholastic abilities should greatly improve.

Koontz, Short, Kalinyak and Noll (2004) conducted a study about school intervention for children with SCA. The research study suggests that children with SCA had significantly fewer absences. Koontz et al. (2004) investigated the feasibility and efficacy of a randomized clinical pilot trial comparing Routine Services (RS) with School Intervention Program (SIP) for children with SCA. Twenty four children between the ages of 8 and 12 years old were randomized to RS or SIP. Koontz et al. (2004) tested three hypotheses: previous experiences in the schools, participants in SIP, comparison of children in the RS condition and children with SCA in the SIP. The results indicate that compared with children receiving RS, children and teachers receiving SIP evidenced more accurate information about SCD, and children with SCA had significantly fewer absences. Koontz et al. (2004) conclusion led to the analysis that a modest
educational curriculum can increase knowledge of children with SCA. Koontz et al. (2004) suggests that a consistent intervention makes a significant improvement in school experiences for children with SCA. It therefore suggests that SIP can increase knowledge of children with SCA and also lower absenteeism.

**Identified Gaps in the Existing Literature**

The review of the empirical research focused on the most pertinent research studies related to the education of individuals with SCD. In the review, the researcher found gaps and insufficient information. The researcher found that the review contained a plethora of recurring themes. The themes were specifically psychological, sociological, medical, and a few educational studies. The researcher found that many of the studies drew upon aspects and interplay from social science, humanities and human biology. While these studies provided erudite, educational and scientific research about the topic of SCD, the researcher found intrinsic limitations within the existing literatures.

Barbarin et al. (1999) conducted structured interviews that determined that families can be psychologically affected by a family member with SCD. While it was determined by Barbarin et al. (1999) that SCD causes emotional stress on the patient, it was not explained that emotional and physical stress causes sickle cell pain crisis. Also there were no explicit or apparent suggestions on how to cope with the stress other than learning to cope. A study by Telfair and Gardner (2000) offers similar evidence. Telfair and Gardner (2000) determined that support groups are very beneficial and valuable to patients with SCD in coping with emotional issues, anxiety, depression and stress. While supportive unions are beneficial and valuable to patients...
with chronic diseases such as SCD, there is still a need to gain a more in-depth understanding of how some individuals cope successfully with intense pain and stress while others cannot.

Given the range of the currently available researches about SCD, individuals with this disease have seldom been asked to tell their own stories from their own individual perceptions and unique experiences. Some of the studies reviewed specifically, on the education of persons with SCD did not explicitly explore their educational experiences and their educational needs. While some of these studies fully recognized the prevalence and challenges faced by students with SCD in the educational arena, the in-school experiences and its tribulations were not thoroughly investigated. For example, Dyson et al. (2010a; 2010b) conducted two studies on school-age children that were very informative and revealing. However, Dyson et al. (2010a; 2010b) did not extensively elaborate or fully utilize any suggestions that may have been given by students in helping to prevent these shortcomings in the future.

Individuals with SCD have been studied repeatedly, but their educational experiences have been examined at a smaller degree. A focus has been on the medical and psychological aspects of the disease. Although there has been a recent study conducted by Dyson (2011) establishing that young students with SCD struggle constantly to find the balance of their somatic (relating to or affecting the body), cultural and social lives. Dyson (2011) also concluded that a field research is needed to find more information from students and their parents how schools could address some of their concerns relating to SCD. More detailed research should be conducted on individuals who have completed higher levels of education.

This research invited participants to reflect upon their earlier educational experiences. In so doing, the researcher of this study endeavored to learn some of the factors that have been
instrumental, or that have enabled some people with SCD to attain a higher level of educational accomplishments. This type of research is needed to uncover why some individuals with SCD succeed while others do not, despite the fact that they come from similar and shared set of health circumstances and health experiences.

While many studies discussed the various challenges and hardships faced by individuals with SCD, none explored the eminent connections between the setbacks and the importance of resilience and motivation in academic achievement. No studies to date have explored the resilience to academic pressures that these individuals must learn and/or put into their studies in order to discover ways to good academic outcome. As research has shown that people can learn and exercise specific resilience, we must also be able learn about how individual resiliency can build itself as ratification or addition to the pursuits of academic success. Thus, this research has uncovered some of the common themes that individuals with SCD have used to demonstrate resilience when faced with adverse and/or challenging life experiences.

No supportive references could be found that bolsters the theory of Social Disabilities. Noll et al. (2007) conducted a longitudinal study to find the social and emotional functioning of students with SCD. Noll et al. (2007) did not fully integrate the concepts that permeate all aspects of psychological, social and emotional needs of students. This longitudinal study should also have included family support and supportive connections between the student, the family and the school. There is still a need to gain a more in-depth understanding of the social and educational needs of students with this disease. The problem with the existing studies on SCD is that they do not acknowledge, reflect or identify some of the current gaps in the literature, nor do they make those gaps explicit in their research. This research has attempted to fill a few of those
gaps of the educational experiences of persons with SCD. Hence, this research has endeavored to improve and to optimize the overall academic experience of persons with this disease.

**Rationale for Social Disabilities Theory (SDT) and Individual Resilience Theory (IRT)**

It is apparent from the existing literature that researchers have not created a SDT or an IRT framework to validate the essence of curiosity of different research contexts for different purposes to collect data for the investigation of the phenomena known as Sickle Cell Disease. SDT and IRT each appealed to the researcher because of their simplicity, theoretical perspective and fluency, distinctive role and interconnectedness to the central purpose of this research. Both SDT and IRT enabled the researcher to conceptualize and frame the research in a manner that yielded meaningful, relevant and valid findings. The theory of reasoning and methodology offered by Oliver and Barnes (1998) for SDT and Masten and Osofsky (2010) for IRT meets the rigorous criteria required for producing theoretically informed accounts of the educational experiences of individuals living with SCA. These two theories are closely interlinked because they both portray and echo many of the realities of the environment in which many individuals with this disease live in.

As there are no universal, all-encompassing, widely used, established or single educational theory that can be applied to the study of individuals living with this disease, and not one particular theoretical framework for conducting this type of narrative research, this fuelled the researcher’s inquiry and quest for theoretical frameworks that are well suited for the research. Hence, the researcher adopted SDT and IRT frameworks to explore, “What are the educational experiences of individuals living with SCA?” Thus, the purpose of this research was intended to explore the educational experiences of individuals living with SCA.
Since there are no published studies that have attempted to use SDT or IRT on this topic, both theoretical frameworks contributed in various ways to the literature on SCD. This enabled the researcher to explain the findings from the perspective of the participants, as well as an opportunity to showcase participants’ educational experiences and the barriers they have faced within their environment. Whilst taking into consideration the factors and conditions that have helped or empowered them to cope better than others with the condition, even though, they are all dealing with the same unpreventable medical condition. Therefore, this research provided a new perspective to the academic work that may improve the scholarship on the topic of SCD by including the educational experiences of persons living with this disease.

Conclusion

Existing studies showed that SCD complications can and often do affect the education of some people who suffer from the disease. The effects of these complications can significantly lead to lifelong failure if proper attention is not given to the patient in their learning years. A failure of family, teachers, peers, institutions and the society at large to recognize and assist the person can and may result in cognitive deficits, poor academic performance, absenteeism, low self-esteem, loneliness, isolation and depression, and also may result into a potential global burden on society. Yet only a handful of studies have been conducted to address the educational aspects of SCD. No such studies have been made thus far to uncover the educational experiences of persons living with SCD from a true reflection of each participant’s experience and through each participant’s own perceptions and own voice. Furthermore, the existing literature on this topic focuses on certain research themes and trends that are salient to the topic of SCD. These
themes are (a) medicine, (b) psychology, (c) sociology, and (d) education. There are still broad limitations and some curtailments, and many discrepancies that exist in these available studies.

**Chapter Summary**

This literature review provided information focused on the research purpose, to explore the educational experiences of individuals living with SCA. A summary pertaining to the history, evolution and characteristics of the disease was also presented, followed by a review of literature pertaining to medical, psychological, sociological and educational aspects of the disease. This chapter offered a comprehensive review of selected literature that have enhanced and contributed to the understanding of this life altering disease. This chapter also presented and selected research studies that supported the contextual issues surrounding this cloudy, hidden and forgotten disease. In this chapter, the researcher also identified the gaps in the existing literature that are critical and relevant to the focus of this research. Additionally, this chapter provided the rationale that guided the use of the two theoretical frameworks, SDT and IRT. The next chapter provides a detailed discussion of the design and methods that were used for the research.
Chapter 3: Research Design and Methodology

Introduction

This chapter endeavored to provide a clear and complete description of the methodology, research approach and procedures that was utilized in the research. It explained in detail why narrative study methodology was selected, the components of a narrative study, and the rationale for the procedures that were used, how data was analyzed and reported. After a comprehensive research approach was outlined, particular attention was given to the researcher’s positionality statement. This chapter ended with a summary to illustrate the connections among the main sections that were presented as part of the methodology and research approach for the research.

Research Questions Restated

The purpose of this research was sought to explore and describe the educational experiences of individuals living with SCA. Thus, the central question that guided this research was: What are the educational experiences of individuals living with SCA?

Research Paradigm

Paradigms shape or structure the practice of qualitative research. Paradigms or worldviews are “assumptions that reflect a particular stance that researchers make when they choose qualitative research” (Creswell, 2007, p. 19). Paradigms are a way of looking at certain assumptions to direct a researcher’s philosophical thinking and/or action. Paradigms identify how worldviews inform and shape or structure the practice of qualitative research (Creswell, 2007). There are several theoretical definitions of paradigms. Mertens (2010) defined a paradigm as a way of looking at the world composing of “certain philosophical assumptions that guide and direct thinking and action” (p. 7). Denzin and Lincoln (1994) defined a paradigm as “a set of
basic beliefs (or metaphysics) that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the “world,” the individual’s place in it, and the range of possible relationships to that world and its parts.” (p. 107). Guba (1990) defined paradigm as a “basic set of beliefs that guides action” (p. 17). Additionally, Creswell (2007) defined paradigm as “a particular stance that researchers make to shape their research when they choose qualitative research” (p. 19). Paradigms have been defined and organized in other ways (e.g., Crotty, 1998; Kuhn, 1996; Newman, 2000; Ponterotto, 2005; Rubin & Rubin, 2012). However, in order to prevent misinterpretation, misunderstanding and misuse of paradigms, the discussion in this research adopted the terminology of Creswell (2007) to describe the worldview that guided this research. Creswell (2007) presented four different paradigms: Postpositivism, Social Constructivism, Advocacy/Participatory and Pragmatism. This research was guided by Social Constructivism paradigm. This paradigm is further explained below.

**Social Constructivism.** Social Constructivism seeks to understand the world in which individuals live and work by developing “subjective meanings of participants’ experiences—meanings directed toward certain objects or things” (Creswell, 2007, p. 20). In Social Constructivism paradigm or worldview, “the researcher looks for the complexity of views rather than narrow the meanings into a few categories or ideas” (Creswell, 2007, p. 20). To gather qualitative data in accordance with Social Constructivism posture, the aim of this research was to conduct a narrative study which explores the educational experiences of individuals living with SCA. Therefore, the goals behind the use of this stance were: 1.) to rely as much as possible on the participants’ experiences in order to make sense and interpret the world in which they live
and 2.) to develop an objective interpretation of the research participants experiences through many points of view and multiple realities.

Social Constructivism paradigm enabled the researcher to apply a philosophical approach to uncover many versions, parts and complexities of opinions, meanings and views from the participants. This paradigm was used to determine where those parts and complexities may interact with each other and in multiple ways. The nature of Social Constructivism paradigm helped to provide a refined view of the commonality that reflects and represents the many realities, shared opinions and shared meanings of the participants. The following sections addresses qualitative research design, research approach and provides a detailed description of the methods that were utilized to address the research question.

**Qualitative Research**

To address the goals of the study, a qualitative research design was chosen because it describes an event in its natural setting (the field) which leads to a rich and deep understanding of the event or situation being studied. Creswell (2012b) wrote that it is appropriate to use qualitative research design when a problem or issue needs to be explored; when an issue needs a complex, detailed understanding; when limited or insufficient theories exist to depict the complexity of the problem being examined. Creswell (2012b) also stated a qualitative research design is suitable when we want to empower specific individuals to share their stories and hear their voices. With this in mind, qualitative research design represents the most appropriate method for carrying out this research, and it was a useful means to gain insight into the experiences of individuals with SCA. Qualitative research is characterized by numerous variations and emergent designs; therefore, a narrative approach was needed to guide and to
broaden the scope of this research. This approach is further discussed in the following paragraphs.

**Research Approach**

There are a wide range of qualitative research approaches organized in various forms and ways, each having its own assumptions or beliefs, methods, procedures, characteristics, attributes, and some with attributes in common (Clandinin, 2007; Plummer, 1983; Sarbin, 1986). Qualitative research is the “umbrella term, writers of qualitative texts have organized…[into] diversity of forms of qualitative research in various ways” (Merriam, 2009, p. 21). Depending on the writer, such diversity of forms could be called approaches (Creswell, 2007) or strategies of inquiry (Denzin & Lincoln, 2005).

Denzin and Lincoln (2005) identified six “strategies of inquiry”– case study, ethnography, grounded theory, life and narrative approaches, participatory research, and clinical research. Jacob (1988) categorized the use of qualitative research into six “major traditions,” – human ethology, ecological psychology, holistic ethnography, cognitive anthropology, ethnography of communication, and symbolic interactionism. Merriam (2009) presents six of the commonly used approaches for doing qualitative research – basic qualitative research, phenomenology, grounded theory, ethnography, narrative analysis, and critical qualitative research. Patton (2002) discusses sixteen “theoretical traditions,” some are familiar classifications, like ethnography, phenomenology grounded theory, narrative analysis and some are less familiar such as orientational, symbolic interaction, semiotics and chaos theory. Tesch (1990) lists forty-five approaches called “orientations,” that are divided into designs (e.g., action
research, case study), data analysis techniques (e.g., content analysis, discourse analysis) and disciplinary orientations (e.g., ethnography, oral history).

There are many approaches for carrying out qualitative research; the specific one chosen for this research was a narrative approach. A narrative approach was chosen because narratives play a fundamental function in structuring and giving meaning to human realities (Sarbin, 1986). Thus, through the selection of narrative approach, this research endeavored to provide a well-organized representation of stories collected from participants’ about the phenomenon of their experiences with SCA, but also gave voice and meaning to the realities of SCA.

**Narrative Approach.** Narrative approach is defined as “a specific type of qualitative design in which narrative is understood [sic] as a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected” (Czarniawska, 2004, p. 17). Josselson, McAdams and Lieblich (2002), Clandinin and Connelly (2000) and Polkinghorne (1988) described narrative approach as a relevant, meaningful and enriching technique for uncovering and interpreting personal stories of human experiences. A narrative approach is made up of many complicated and multilayered specifications that involves bringing to light the importance and significance of a particular story of a person or group of people and identifies reoccurring themes and patterns from the stories told (Czarniawska, 2004; Polkinghorne, 1988; Riessman, 2008; Sarbin, 1986). Narrative approach captures stories of individuals using practical and specific insight that are focused on the representation and reporting of each individual’s experiences (Connelly & Clandinin, 1990; Josselson et al., 2002; Lieblich, Tuval-Mashiach & Zilber, 1998).
Narrative approach assumes multiple forms. Clandinin, 2007, Josselson et al. (2002), Lieblich et al. (1998), Plummer (1983) and Polkinghorne (1988) describe five of the most popular approaches used in narrative research, namely a biography or a biographical study, an autobiography or autoethnography, a life history, a personal experience story and an oral history. This research sought to explore the educational experiences of individuals living with SCA. Therefore, a personal experience story approach used in narrative research represents the best ways to collect stories from several different individuals. This approach gave a human voice to the marginalized stories of individuals whose personal experiences may not otherwise be heard. Furthermore, the use of a personal experience story provided insight and unique perspectives into the lives of individuals with SCA. The following sections describe in detail the methods and the procedures that were used in data collection and data analysis.

**Site and Participants**

This research explored and described the educational experiences of individuals living with SCA. One to four participants fall within the adequate sample size for a narrative research in order to get a credible and reliable representativeness of the data (Clandinin, 2007; 2008; Connelly & Clandinin, 1990; Lieblich et al., 1998; Polkinghorne, 1988; Riessman, 2008). The targeted group of interest for this research therefore consisted of four persons who have progressed through the educational system. The number of people was determined in an effort to have a minimum of three participants who meet the criteria in this research in the event that a potential participant with the particular preference characteristic was unable, unavailable, or unwilling to participate. Furthermore, this number of people also provided the opportunity to gain greater understanding of SCA.
**Sampling Procedure**

**Criterion sampling.** Criterion sampling was used to select participants for this research and to ensure a strong “quality assurance efforts” (Patton, 1990, p. 176). The primary participants consisted of four persons who met the following criteria:

1. Diagnosed as having SCA.
2. Have earned an associate’s a bachelor’s, a master’s and/or a doctorate degree.
3. Have reached the age of 25 years or older.
4. Ready and willing to take part in the study.

Criterion sampling is used in research to understand cases that are likely to be information-rich because they may reveal major system weaknesses that become targets of opportunity for program or system improvement” (Patton, 1990, pp. 176-177). Patton (1990) states that criterion sampling is best used for in-depth qualitative analysis of study that meets some predetermined criterion characteristics and importance. To this end, criterion sampling was a good method to select individuals who met the criteria for this research. In addition to criterion sampling, snowball sampling was also used for this research.

**Snowball sampling.** Snowball sampling technique is a non-probability sampling approach for locating and recruiting research participants through the identification of an initial participant or others who are trusted members in a community who are asked to assist the researcher in identifying other potential participants (Creswell 2012a, Patton, 1990). This technique will allow the researcher to “accumulate new information-rich cases” (Patton, 1990, p. 176). Snowball sampling was used for initiating the recruitment of volunteers for this research. That is, by word of mouth from trusted community members, recommendations from friends and
family, and by contacting potential participants based on prior knowledge of the researcher that they met the predetermined eligibility criteria. Snowball sampling enabled the researcher to gain access to data and information directly from participants willing to take part in the research.

**Recruitment and Access**

Recruitment of volunteers was concentrated on finding individuals who were best suited for the conceptual design plan of the research. That is, the educational experiences of individuals living with SCA. Recruitment of participants was based on the selection of individuals who met a predetermined set of criteria: (1) diagnosed as having SCA, (2) have earned an associate’s, a bachelor’s, a master’s and/or a doctorate degree, (3) have reached the age of 25 years or older, and (4) ready and willing to take part in the study. After the researcher obtained approval from the Institutional Review Board (IRB), the researcher contacted trusted members of the community, friends and family members in order to gain access to names of individuals with SCA who possibly would be willing to participate in the study. Access to individuals was secured by contacting prospective participants via email or telephone. A recruitment letter (Appendix D) was then sent via email to these individuals. In the letter, prospective participants were informed of the nature and purpose of the study and its significance.

The recruitment letter explained that the study will consist of two open-ended interviews which may be conducted either by Skype® or telephone. The recruitment letter stated that the first interview would last approximately 60 to 90 minutes and the second would last approximately 60 minutes. The recruitment letter included the Informed Consent Form (Appendix F) as an attachment. The letter requested that individuals interested in volunteering as participants should contact the researcher via email or by telephone for more information. The
researcher’s contact information was listed on the recruitment and consent letter. The letter also stated that individuals who were interested are invited to learn more about the study at a time convenient for them using Skype® or telephone.

**Informed Consent and Ethical Considerations**

Prior to contacting any potential participants, a proposal was prepared for an approval in order to conduct research from the Northeastern University’s IRB. This proposal included: Definition of Terms (Appendix A); Human Subject Protection Training Certificate (Appendix B); Permission Letter to Conduct Interview (Appendix C); Letter of Invitation to Participate in Research–Recruitment Letter (Appendix D); Application for Institutional Review Board Approval (Appendix E); Consent to Participate in Research–Informed Consent Form (Appendix F); Initial Intake Protocol Form (Appendix G); Questionnaire (Appendix H); and Open-Ended Interview Questions (Appendix I).

Informed consent was obtained from participants in order to conduct this research. Participants were assured confidentiality that their identifying information (e.g., name, home, work and email address) will not be made available to anyone who is not directly involved in the research. To ensure that participants confidentiality remains intact during and after the study, participants were given pseudonyms (code names) to assure that they will not be linked to the research. Direct information that could reveal participants’ identities were removed from all documentation. Participants were assured that this research will not harm them, and that any information collected will not damage, hurt, harm or cause risks and discomforts to them in any way. Safeguards and special instructions and/or precautions laid out by the IRB were implemented to minimize possible risks, and chance of harm to each participant. The researcher adhered in accordance with the rules and regulations set forth by the IRB regarding protection of
human research subjects, e.g., informed consent, privacy protection and confidentiality agreements all through the course of research project.

**Data Collection**

Data collection is “a series of interrelated activities aimed at gathering good information to answer emerging research questions” (Creswell, 2007, p. 118). Data collection in qualitative research can be carried out by employing a variety of techniques or by choosing one particular technique (Potter, 1996). For a narrative study, the data collection techniques could be open-ended interviews, reflective journals, participant observations, examination of documents or a combination of any of the techniques (Clandinin, 2007, 2008; Josselson et al., 2002; Potter, 1996). Denzin (2005) and Potter (1996) suggest that data collection methods in qualitative research could be grouped into four basic types of information: (1) observation ranging from nonparticipant to participant; (2) interview ranging from closed-ended to open-ended; (3) documents ranging from private to public; and (4) audiovisual materials including materials such as photographs, compact disks and videotapes.

Miles and Huberman (1994) and Wolcott (1994) posit that data collection and analysis are best conducted simultaneously in qualitative research to allow for the inclusion of many different kinds of data collection process, room for more freedom and necessary flexibility. Therefore, data collection and data analysis occurred in a cyclical and redundant process until data were reduced into patterns and themes through “a process of coding and condensing the codes” (Creswell, 2007, p. 148) into tables, figures and a detailed discussion. Three types of data collection techniques were utilized for this research: (1) open-ended interview, (2) document reviews, and (3) reflective memos.
Open-ended interview. For the purpose of this research, open-ended interview technique was utilized as the primary method of qualitative data collection. “A qualitative interview occurs when researchers ask one or more participants general, open-ended questions and record their answers” (Creswell, 2012b, p. 217). To ensure that the two interview sessions preceded smoothly, each participant were interviewed at a specified time convenient for each of them utilizing a telephone. This gave each participant the opportunity to have the most comfortable discussion. To furthermore ensure that both interviews proceeded smoothly, on the day prior to each interview, the researcher confirmed that the arrangements of date and time are still convenient and acceptable for them. The researcher also made sure that all the necessary equipments and devices, e.g., the audio recorder, batteries, phone charger, a pen and a writing pad were at the ready. Open-ended interview was supplemented by the researcher’s own reflective memos compiled during and immediately following the interview process. This served as another effective method to reduce the risk that the results, interpretations and conclusions were not misleading, biased or invalid (see Appendix I for open-ended interview 1 and 2 questions).

Document review. When a researcher uses multiple data collection, it is for the purpose of gaining a more detailed understanding of the narrative study (Polkinghorne, 1988). Collection of data through multiple sources is an effective method of reducing the risk that the interpretation of the results may be biased, unreliable or invalid. In general, documents are any preserved recording of person’s recollection of his or her thoughts or actions, such as in books, diaries, letters, drawings, newspapers, photographs, manuscripts and online discussions (Potter, 1996; Rubin & Rubin, 2012). This form of data collection technique may reveal a difference between
statements made by participants during open-interviews and when the documents are examined. It is important to determine if such difference exists and to examine patterns and themes that emerge from the two sources of data (Clandinin & Connelly, 2000; Potter, 1996). Upon examination of the documents reviewed, it revealed similar findings to the data obtained from the two open-ended interviews. Document review is a rich and an informative method of supplementing other qualitative methods. Therefore, it was used in this research to portray and interpret participants’ stories.

Document review was utilized as a method for analyzing and interpreting the data collected for validity and trustworthiness of information. This provided the researcher with rich and credible information that was used to address the concerns of validity of the two open-ended interviews. The researcher collected documents consisting of photographs, published articles, verses from the bible and newspaper account. Each document that was provided to the researcher by the participants was examined. Each participant was asked to bring in 1 or 2 artifacts that could be used to describe or that represent their personal experiences with SCA (see Appendix G and I). Participants were asked to blank out their names or any other identifying marks on the documents to protect their identities as a participant in the study. The collection of these documents was also used by the researcher to elicit and capture additional data from each participant’s point of view. Document review as a data collection method provided extra valuable data that was used to gain enhanced understanding of the stories that were told by each individual studied. It also served as a way of strengthening the credibility of the interpretations derived from this research.
Reflective memos. Corbin and Strauss (1988) define memos as “a record of analysis, thoughts, interpretations, questions and directions for further data collection” (p. 110). Reflective memos are an important element of qualitative data collection and analysis. Corbin and Strauss (1988) point out that memoing allows the researcher to share his or her experiences and perspectives during the entire course of a research project. Roulston (2010) recommends this type of data collection technique because it provides researcher’s ways to use their own words and interpretations in addition to the participant’s words and phrases to review and reflect on the data collected. Reflective memos were used during this research to record ongoing development of ideas, decisions, themes, patterns, codes and insights that emerged during the research process. Memos served as a way to capture the non-verbal communication. Furthermore, the researcher was able to write about her personal reflections regarding her own perceptions, reactions, feelings and interactions with the participants. Reflective memos were maintained throughout the qualitative research process of member checking, data collection and analysis. Overall, reflective memos promoted critical thoughts about different aspects of the research, enrich the value of the findings, and supported the validity and the credibility of the outcome of this research.

Interview Process Overview

This research is designed to explore the educational experiences of individuals living with SCA. This research included two open-ended interviews with 4 individuals identified as having SCA. An interview protocol was created (see Appendices G, H and I), which included open-ended questions and probes throughout the interviews to gain a more comprehensive description of participants’ educational experiences. The researcher sent out invitations to
participants asking them to take part in the study (see Appendix D for the recruitment letter). Once the researcher received a confirmation from each participant that he or she was willing to take part in the project, the researcher then proceeded with an initial intake meeting. The following paragraphs will explain the procedures that were used to carry out the interview process for the study once an individual agreed to participate in the research.

**Initial Intake Meeting**

This meeting served to introduce the researcher to each participant as a way of establishing rapport and getting-acquainted and it enabled greater and easier communication. Each potential participant received a telephone call to be formally invited to take part in the research. The purpose of the research was briefly explained. Each participant was given sufficient time to ask questions as needed about the project. Once a potential participant agreed to take part in the research, he or she was informed that any information collected will be strictly confidential. That is, his or her name, address, telephone number or other identifying features will not be used in any analysis or in any reporting of the research. The researcher explained the participant’s role and everything that will occur during the course of the two interviews. The consent form was also read and reviewed with each participant. Each participant was assured that there will be no risks, inconveniences or discomforts associated with participating in the research. Each participant was also assured that participation is voluntary, should he or she decide to take part in the study. Participants were also informed that they may elect not to be part of the research, and also may withdraw from the research at any time.

Each participant that volunteered was then asked if he or she would like to schedule a time for two formal open-ended interviews. Participants were informed that both interviews would take place within a three to seven day period and may be conducted either by Skype® or
telephone. Participants were informed that interview questions will be prearranged to follow a progression of their experiences with SCA, from general to specific questions. That is, the first open-ended interview will last approximately 60 to 90 minutes focusing on their life history, personal experiences and present day experiences in relation to the topic. The participants were informed that the second open-ended interview will last approximately 60 minutes allowing them to reflect upon the meaning of the experiences from the first interview. The specific questions that were explored were included in an interview protocol (see Appendix I).

The two-open ended interviews, the 60 to 90 minutes duration format and the three to seven day spacing of interviews were crafted based on Seidman's (2006) three-in-depth interview and 90-minute duration and spacing format. Seidman’s (2006) structured approach and protocol, each preferably spaced 3 to 7 days apart involves “conducting a series of three separate interviews with each participant” (p. 16). The series of three separate interviews described by Seidman (2006) are: (1) focused life history, (2) the details of experience, and (3) reflection on the meaning.

Seidman (2006) recommends adherence to the three-interview structure because “each interview serves a purpose both by itself and within the series” (Seidman, 2006, p. 19). Although Seidman (2006) acknowledged that alternatives to the structure and process of the three-interview series are acceptable and “can certainly be explored, as long as a structure is maintained that allows participants to reconstruct and reflect upon their experience within the context of their lives (pp. 21-22). Given that there are a wide range of procedures for interviewing and “there are no absolutes in the world of interviewing” (Seidman, 2006, p. 22), a
series of two separate interviews with each participant was sufficient for the purpose of this research to elicit meaningful, rich, thick descriptive data from participants.

Finally, the researcher asked each participant if he or she would answer a 5 to 10 minute questionnaire (Appendix H). Participants were informed that the intent was to gather basic background information to create a summary table and a written description that would be associated with each participant in the research. The researcher requested that the form should be completed and returned to her within 3 days. Fortunately all the participants willing completed the questionnaire within the allotted time. This questionnaire was especially important because it provided the researcher with the necessary information about each participant’s gender, age, ethnicity, race, educational level and occupation, marital and family status. The purpose of the questionnaire was to facilitate a characterization that was associated with each person. It also provided the researcher with more detailed and accurate information about each participant. The following paragraphs will summarize the storage protocol for the collection of data.

**Data Management and Storage**

Confidentiality issues was recognized and considered at every stage of the research process. Confidentiality of participants was protected by “masking their names in the data” (Creswell, 2012b, p. 175). High-quality audio recorder was used during all interviews. Recording of interviews on the researcher’s Digital Flash Voice Recorder and Apple iPhone was downloaded and saved onto the researcher’s personal USB flash drive, portable external hard drive and laptop computer accessible only to the researcher. To ensure security and confidentiality, all files were password-protected, making them inaccessible to others. In order to maintain participants confidentiality in the report, pseudonyms (code names) were used in place of identifying information so that participants’ identities could not be recognized by others.
Once data was collected through interviews, the audio was immediately transcribed and transferred from spoken to written word to facilitate analysis. For added confidentiality, interviews were transcribed word for word (verbatim) directly by the researcher. Transcription was typed and formatted in Microsoft Word documents. The researcher’s laptop computer was be password protected with a firewall system at all times and was kept in a highly secured location at the researchers’ home along with other important and sensitive documents to ensure the security of the data. The laptop computer when not being used to for the research was kept in secured location under lock and key prevent unauthorized access to computer and files. Backup copies of computer files were stored in a locked safe at another secured location outside of the researcher’s home.

Data (hard-copy materials containing participant’s information, and all electronic data) was permanently deleted and destroyed 2 months after the completion of the research. Any signed documents will remain intact and will be kept in a locked safe. Such documents will be destroyed 3 years following the completion of the research. Any data collected during the course of this project will be used solely for the researcher’s doctoral thesis, and may be used in her future lectures, seminars, presentations, books, documentaries, academic journals and other publications relating to the topic in the research. In these instances, confidentiality will still be maintained for all participants and their information will continue to be stored in a secured manner. The following sections outline a detailed description of the data analysis process, computer programs and techniques that was utilized in the exploration of the research.

**Data Analysis**

Data analysis in qualitative research consists of preparing and organizing the data for analysis, then reducing the data into themes through a process of coding and condensing the
codes, and finally representing the data in figures, tables, or a discussion (Miles & Huberman, 1994). In a narrative study, the goal is to understand and inquire into the specific life experiences or particular incidents of individuals through “collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus” (Clandinin & Connelly, 2000, p. 20).

Clandinin and Connelly, (2000) described three simultaneous commonplaces (dimensions) for undertaking narrative inquiry, temporality, sociality and place. Clandinin and Connelly, (2000) states that “all three commonplaces is, in part, what distinguishes narrative inquiry from other methodologies” (p. 20). Temporality “we mean events under study are in temporal transition” (Connelly & Clandinin, 2006, p. 479). Sociality attends to personal and social conditions simultaneously (Connelly & Clandinin, 2006). Personal conditions refers to “feelings, hopes, desires, aesthetic reactions and moral dispositions” (Connelly & Clandinin, 2006, p. 480) of the researcher and participants. Social conditions refer to “the milieu, the conditions under which people’s experiences and events are unfolding” (Connelly & Clandinin, 2006, p. 480). Place is define as “the specific concrete, physical and topological boundaries of place or sequences of places where the inquiry and events take place” (Connelly & Clandinin, 2006, p. 481). Clandinin and Connelly, (2000) and Connelly and Clandinin, (2006) posit that attending to the commonplaces will allow a narrative researcher to study the complexity of the participant’s life experiences from a relational composition.

There are numerous definitions, views and methods of qualitative data analysis. Lieblich et al. (1998) identified two main perspectives, holistic and categorical. Lieblich et al. (1998) stated that “upon looking at different possibilities for reading, interpreting, and analyzing life
stories and other narrative materials, two main independent dimensions emerge—those of (a) holistic versus categorical approaches and (b) content versus form” (p. 12). Lieblich et al. (1998) divided the two main independent dimensions into four different modes of narrative analysis:

1. Holistic-Content, which takes into consideration the entire story and focuses on its content. The analysis concentrates on one major theme to create a rich picture of a unique individual from the story of the person’s life.

2. Holistic-Form, which looks at the complete life story but focuses on its formal aspects rather than its contents. This method focuses on plot analysis to find three basis patterns or graphs of progression, regression and a steady line.

3. Categorical-Content, which focuses on the content of narratives as manifested in separate parts of the story, irrespective of the context of the complete story. This method looks at a broader category or unit called event-explanations units to provide attributions to various events in the life stories. This method leads to the detection of individual attribution styles based on rich and varied narrative materials such as quotations from political speeches, therapy transcripts, diaries and personal letters.

4. Categorical-Form, which looks at formal aspects of separate sections or categories of a life story. This method focuses on plot analysis, but attends only to parts of the description of the story when evaluating or interpreting events. This method can be used for a variety of verbal behaviors, procured from different sources, such as diplomatic communication, speeches, interviews, magazine editorials, and so on. (Lieblich et al., 1998, pp. 15-18)
For the data in this project, the researcher followed primarily “a prototypical series of steps taken in most of the variations of content analysis” (Lieblich et al., 1998, p. 112). The process of analysis in this research was also based on Lieblich’s et al. (1998) categorical-content analysis mode. Categorical-content analysis was selected and utilized because it enabled the researcher to look at separate parts of the narrative materials and to process each part “analytically, namely by breaking the text into relatively small units of content and submitting them to either descriptive or statistical treatment” (Lieblich et al., 1998, p. 112).

One of the goals of the research was to identify common themes and patterns within the participants’ description of their experiences. Categorical-content analysis focused on the content of the stories generated from the narrative materials. This method lead to a systematic discovery of themes and patterns that was inherently distinctive in the data. It also conveyed “the richness and depth of the narrative material” (Lieblich et al., 1998, p. 126). Thus, the rationale behind the use of this form of analysis as opposed to other modes or perspectives is that, it allow enabled the researcher to extract relevant “parts of the life story out of the whole.....based on the length, detail, intensity and emotional tonality of the utterances” (Lieblich et al., 1998, p. 126). The following paragraph discusses the computer program and techniques, and the process of content analysis (categorical-content analysis) that was utilized in carrying out this research.

**Data Analysis Procedures.** Coding is an important phase of qualitative data analysis. It involves the use of words, phrases and sentences found in the transcript to form codes or tags or labels that can be used to categorize themes, identify recurring themes and meaningful patterns. The tasks of data analysis for this research were accomplished manually by incorporating primarily the guidelines specified by Lieblich et al. (1998) for categorical-content analysis.
Categorical-content analysis identifies “various themes or perspectives that cut across the selected subtext and provide a means of classifying its units – whether words, sentences, or groups of sentences” (Lieblich et al., 1998, p. 113). Categorical-content analysis is “a circular procedure that involves careful reading, suggesting categories, sorting the subtext into categories, generating ideas for additional categories or refinement of the existing ones, and so on” (Lieblich et al., 1998, p. 113). This approach to narrative analysis involves sorting and breaking (i.e., codes) descriptive information into self-contained categories to find emerging themes, generate ideas for new categories, repeating the method, sorting and drawing conclusions from formulated themes and patterns (Lieblich et al., 1998).

**The Process of the Content Analysis for the Research**

Content analysis was conducted through inductive approach in the analysis of the data. This allowed the researcher to discover categories and patterns from dominant themes that are inherent in the raw data from the participants’ experiences. Inductive content analysis focuses on raw textual data, creating categories, and abstraction to establish clear links between the research objectives and the summary of findings derived from the raw textual data (Corbin & Strauss, 1990). Inductive approach provided an easy to use set of procedures that produced clear, reliable and valid findings. The procedures for reading, analyzing and interpreting the data collected are summarized in the following paragraphs.

**Categorical-Content Analysis Process**

**Open-ended interviews.** After the two open-ended interviews were transcribed, the transcripts were analyzed and coded. Categories and codes were added during the research process as they emerged. This allowed the researcher to become very familiar with descriptive information collected. The steps taken in most of the variations of categorical-content analysis
were used for this research. These steps from Lieblich et al. (1998, pp. 112-114) are summarized as follows:

1. Selection of the Subtext on the basis of the research question, all the relevant sections of the text were marked and assembled to form a new file. Text were reviewed as openly as possible to define major content categories that emerged from reading; and grouped into a matrix of rows and columns of related content categories. This enabled the researcher to become very familiar with descriptive information collected. It also paved the way for categories on the specific purpose of the research to emerge as the analysis continues.

2. Definition of Content Categories. These are various themes or perspectives that cut across the selected text (words, sentences or groups of sentences from transcription). Content categories were determined by reading the text as openly as possible (inductively) and by defining the major content categories that emerged from the reading. Content categories were grouped based on the specific research theories, central research question, interview questions, research goals etc. Interview transcripts were continuously read and re-read to search for new ideas to be generated for additional categories and for refinement of the existing ones, and on.

3. Sorting the Material into the Categories. Separate words, phrases and sentences were assigned to relevant categories. Relevant categories were organized, sorted into similar ideas. This process was repeated until a list of descriptive themes were created and summarized. A matrix of rows and columns was created to display and organize descriptive themes into similar categories. Similar categories were condensed, organized and grouped into themes of related topics, patterns, assumptions, issues and underlying ideas. Themes were analyzed and
summarized into an informational chart for each interviewed participant and for commonalities that cut across each interviewed participant’s point of view.

4. Drawing Conclusions From the Results. Words, phrases and sentences in each category were counted, tabulated, and ordered by frequency to show relationships among words to analyze the data. Contents collected in each category were also used descriptively to formulate meanings and to create a picture for each participant’s experience and within the shared experiences of all participants.

Reflective memos and document reviews. Reflective memos and document review were thoroughly examined separately multiple times to find examples of themes, patterns and commonalities that were representative of particular meanings and/or specific experiences of each participant as well as on any commonalities that cut across each interviewed participant’s point of view. Reflective memos were used to construct and verify the information provided by participants. Document review was used to support the responses of the participants and to provide additional evidence about the nature of participants’ experiences. These procedures verified and confirmed that the findings and results are appropriate before labeling them as final results. Interpretations and meanings that emerged from the reflective memos and documents reviewed were verified for their credibility, their reliability, their sturdiness, their validity and for trustworthiness of the findings. This helped to provide a record of the meanings and implications derived from the data. Data were summarized; results were analyzed and interpreted to provide a linkage to the specific purpose of the research. Data analysis was an ongoing procedure until the final report of the project was completed. In the following sections, trustworthiness issues were discussed.
Trustworthiness

Qualitative research can be evaluated by its trustworthiness. Miles and Huberman (1994) proposed five standards to ensure the trustworthiness or quality of conclusions drawn from qualitative data. These five standards are: (1) objectivity and confirmability, (2) reliability, dependability and auditability, (3) internal validity, credibility and authenticity, (4) external validity, transferability and fittingness, and (5) utilization, application and action orientation (pp. 277-280). Lincoln and Guba (1985) presented four slightly different constructs: (1) credibility, (2) transferability, and (3) dependability, and (4) confirmability.

In research, the assessment of trustworthiness is crucial. To ensure efforts of trustworthiness in this research and to maintain the trustworthiness of the research findings, the researcher addressed the issue of trustworthiness using three validation strategies (1) threats to internal validity, (2) transferability, and (3) confirmability. To enhance each of these three validation strategies mentioned above and to be sure that there was no misinformation; a number of techniques were utilized to check that the researcher understood the participant’s perceptions accurately instead of jumping to conclusions about participant’s perceptions. Member checking and rich, thick description are the two techniques that were used to enhance the data analysis and interpretation of findings in this research. These techniques are further explained in the following paragraphs.

**Threats to Internal Validity.** Internal validity refers to the appropriateness, meaningfulness and usefulness of the inferences made based on the data collected (Clandinin & Connelly, 2000; Connelly & Clandinin, 1990). Researcher bias and familiarity is a possible threat to internal validity and confirmability of this research because the researcher has knowledge and insights into the topic. To minimize threats to internal validity of the results of
the research, a number of techniques were adopted to check the perception of participants, and to ensure that there were no false or misleading information about the issues raised in the interview questions. To present objective knowledge of the issues raised by participants, the researcher attempted to minimize her own personal biases, emotions, feelings, thoughts and opinions by acknowledging her positionality so that these ideas did not get in the way of the research.

**Member Checking.** In a qualitative study, member checking is primarily used to check the validity of the report. The researcher solicits participants’ views of the credibility of the findings and interpretations (Lincoln & Guba, 1985; Merriam, 2009; Miles & Huberman, 1994). Member checking is considered to be “the most critical technique for establishing credibility” (Lincoln & Guba, 1985, p. 314). These techniques ensured that interpretations and conclusions of the findings made sense and are credible. Thus, interpretations adequately described participants’ points of view and validly represented the aim of the research study. Member checking was completed by sending an electronic copy of the transcripts via email to each interviewed participants for them to review the report for accuracy. This process served as a method which enhanced the validity and interpretations of the research findings.

**Transferability.** Transferability is an important step in the qualitative research process because the main idea is to provide a rich, thick contextualized understanding of the study and to draw broad inferences that can be transferred or extended outside the study situation to a wider context or settings (Lincoln & Guba, 1985). To enhance transferability and the possibility of the findings of the research, careful attention was given to the selection of the participants. The researcher ensured that only participants that have met the predetermined criteria were included. Thus, the use of criterion and snowball sampling methods were credible strategies to show that
participants are representative of the intended population. Thus, the researcher was able to validate the results back to the participants.

Another technique for enhancing transferability is rich, thick descriptions of the contexts, activities and participants involved in a study (Lincoln & Guba, 1985). Lincoln and Guba (1985) note that transferability is the responsibility of the researcher to provide readers with sufficient description of the activities of interest and participants involved in the study. To further accomplish the task of transferability as stated above, rich, thick descriptions was used when describing the participants in this research. This technique offers readers’ abundant details that will enable them to make decisions about whether the findings of this research are transferable to other contexts or settings. Rich, thick description is further discussed in the following paragraph.

**Rich, Thick Description.** The most commonly used strategy to enable transferability is rich, thick description. Denzin and Lincoln (1994) and Lincoln and Guba (1985) described rich, thick description as a way of achieving a type of external validity or generalizability that typically applies only to certain aspects of quantitative methods. In thick description, “the voices, feelings, actions, and meanings of interacting individuals are heard” (Denzin & Lincoln, 1994, p. 83). The researcher endeavored to create rich and meaningful descriptions and inferences by describing the participants in sufficient details. The researcher ensured that these descriptions were rich and thick by using adequate evidence, strong quotations and verbs from the transcripts, documentary evidence and reflective memos to describe each participant. This technique helped to form a detailed description that was used to contextualize the research findings. This technique also enabled the researcher to convey as much as possible about each participant. It
may also make it possible for readers to decide if the findings of the research can be extended to other individuals, other contexts and to other situations.

**Confirmability.** Confirmability assumes that “the conclusions depend on the subjects and conditions of the inquiry rather than that on the inquirer” (Miles & Huberman, 1994, p. 278). Miles and Huberman (1994) assert that “a key criterion for confirmability is the extent to which the researcher admits his or her own predispositions” (p. 65). In the following sections, the researcher acknowledged and explained her own biases, positionality and opinions in order to enhance and achieve confirmability. The researcher stated explicitly her assumptions and affective states as it relates to her own unique experiences and contributions as a sickle cell anemia patient. To furthermore accomplish these goals, the researcher attempted to minimize biases so that the interpretations are explicitly reflective of each participant’s points of view and meanings, rather than being a reflection of the researcher’s personal beliefs, perceptions, or biases. In an effort to clarify the researcher’s experiences, assumptions, perceptions, biases and affective states related to the overall topic, the following sections includes a discussion of the role of the researcher and positionality.

**Researcher’s positionality.** As a West-African woman from the southwestern part of Nigeria, I feel strongly about the role education plays in my life and I believe that education allows for a sense of empowerment. However, I know that many students face a variety of difficulties and challenges during the educational process, particularly for those with disabilities and special health needs. The sense of empowerment can easily be lost by the levels of increased frustration caused by their inability to keep up with their studies and relationship with their peers. Family and school support can be one of the salient factors in achieving the level of motivation
and dedication needed to reduce some of the frustration students with SCA go through. In order to keep up with academic studies and to strive towards academic achievement under difficult circumstances, I believe family and school support can have a positive impact on the educational development of students with SCA.

Education is a continuous learning process that may be accomplished through hard-work, dedication and support from family, peers and school. If students have the proper support, while dealing with the uncertainties of not knowing when a SCA pain crisis is about to be triggered, they will hopefully be able to cope with their academic studies. I believe that my positionality preferences and perceptions are reflective of my family’s inherited ability for determination, confidence and academic achievement, along with my own coping mechanisms, my own individual strengths, abilities and perseverance to rise to these challenges. In conclusion, it is my hope to strive to open a pathway for others with SCA to reach their highest potential while learning to maintain a positive outlook.

The role of a researcher. As a researcher, particularly one who is more familiar with the methods of qualitative research, my role is very complex and unique. My role was first, to identify an insightful and meaningful topic that required a comprehensive knowledge of the topic. Secondly, I formulated a clear and answerable research question, and then developed a comprehensive research design. As a researcher, I was also responsible for reducing any personal biases that I may have had for qualities of validity, confirmability and trustworthiness in a qualitative research project.

In the case of this particular research, I brought a unique perspective because of my own unique experiences as a sickle cell anemia patient. Hence, I acknowledge that I entered this
project with the assumption that a person with SCA has feelings that are similar to mine. Therefore, I attempted not to affect or sway research participants in such a way that influenced their thinking or forced responses that I personally believe or assume a person living with SCA should have. I ensured that the interpretations are explicitly reflective of the research participants’ experiences, meanings and from their own points of view. The following paragraphs include a presentation of my unique contributions and accomplishments, and how my parents’ dedication to and for education have been engraved in me and have helped shaped me into the person I am today; and that I will be throughout my life.

**Unique contributions.** My contributions and accomplishments have grown from four areas: (1) personal background, (2) educational background, (3) professional background, and (4) my own family experiences. This research was inspired by my knowledgeable background around the issue of SCA based on my personal experiences as a person living with the disease; and my own educational achievements including, a Bachelor of Science in Social Science: Human Development and Family with a certification in Elementary Education (1-6), a Master of Education in Special Education Mild to Moderate Disabilities (PreK-12), and a Master of Arts in School Administration (K-12). Also more specifically, having spent many years prior as a Special Education Resource and Inclusion Teacher, Special Education Compliance Facilitator, Special Education Department Chairperson, Inclusion Lead Teacher, and Direct Instruction Lead Teacher in K-12 public schools, I had developed a very keen interest in the education of students with disabilities and special health needs.

I am fortunate and privileged to have grown up within a family unit that always promoted education, academic leadership, political leadership and administrative qualities. The value and
importance of being an advance degree professional was and still is a top priority in my family, this was not just hoped for, but it was expected. Both my parents are well-educated and both instilled in me at an early age that a high-class education was a necessity in order to be socially and intellectually accepted in the larger society. My father, Professor Wande Abimbola received a B.A. (Honors) in History, University of London, 1963; a M.A. in Linguistics, Northwestern University, 1966; a Ph.D. in Literature (Yoruba and Ifa), University of Lagos, 1969 and was inaugurated as a Full Professor of Linguistics and African Languages, University of Ife, 1976 (now Obafemi Awolowo University-OAU, the foremost university in Nigeria and the 14th of over 620 accredited universities in Africa).

My father taught at three Nigerian universities, University of Ibadan, University of Lagos and the University of Ife; and also several universities in the United states including, Harvard University, Boston University, Amherst College, Colgate University and Indiana University Bloomington. He also worked as a Dean of the Faculty of Arts, University of Ife; head of the Department of Linguistics and African Languages, University of Ife; a former University of Ife Vice-Chancellor (known as university president in the United States); a Senate Majority Leader of the Federal Republic of Nigeria and a Special Advisor to the President of the Federal Republic of Nigeria. My father is a renowned leader and master of Ifa and Yoruba (Orisa) religion which has approximately 100 million parishioners worldwide, and the Awise Awo Agbaye (Spokesman of Yoruba [Orisa] religion and Ifa Worldwide).

My mother, Mrs. Felicia Olanrewaju Abimbola received her Midwifery education and license in the Baptist Training Center Ire, Osun State, Nigeria, 1959. My mother worked as a midwife in hospitals caring for women during pregnancy in antenatal care clinics (also known as
prenatal), delivering babies and caring for newborns, as well as having six children of her own. She later studied Stenography (Shorthand) at the University Ife, Nigeria, 1977. She became the Head Secretary and Confidential Secretary (apart from her duties as head secretary) of the Department of Nursing at the University Ife. She was the supervisor of fifteen plus typists, office clerks and office messengers. As a result of my parents achieving these goals, I was fortunate to have been brought up in a family environment that instilled into me higher educational values and I feel very fortunate to have my parent’s support and encouragement. I also feel very privileged as each of my siblings’ education ranges from at least two to three MAs, one JD, one MBA, one PhD and one sibling with two PhDs. My family’s dedication and zeal for education continues to inspire me to strive for growth, and boosts my motivation to continue pursuing my educational, my career aspirations and lifelong dreams.

Protection of Human Subjects

A Doctoral Thesis Proposal (DTP) was submitted to the researcher’s advisor before beginning this research. The DTP structure served as a roadmap that was followed during the research project. To secure Institutional Review Board (IRB) application approval, the specific procedures and policies of Northeastern University for IRB approval was followed prior to beginning the project and before any process of collecting and analysis data. The required training course and test set by the National Institutes of Health (NIH) Office of Extramural Research to obtain a certificate of completion on “Protecting Human Subjects Research Participants” was successfully completed on the 3rd of June, 2012 through Northeastern University’s Research Website (see Appendix B). IRB approval ensured knowledge of ethical standards in research and indicated adherence to research ethics and the protection of all human
subjects. The research process using human subjects as interviewees only began after the review and approval of procedures by the IRB (see Appendices E and F for IRB process for protection of human subject research participants).

**Chapter Summary**

This chapter has outlined the steps that were taken in collecting and analyzing data for the research. An in-depth research design was presented, including descriptions of the qualitative design and the approach that was used to guide these methods. This resulted in a thorough and comprehensive research project. Research participants were drawn using criterion and snowball sampling techniques. Member checking and rich, thick description were utilized to enhance the trustworthiness and quality of the findings. In this chapter, ethical considerations in research were also discussed. Finally, the researcher’s role, background in education and teaching, family background, unique contributions and positionality as it relates to the topic were also discussed.
Chapter 4: Research Findings

Introduction

The purpose of this research was intended to explore and describe the educational experiences of individuals living with SCA. Thus, the purpose of this chapter is to present the findings related to the research project. The research question for this project is: What are the educational experiences of individuals living with SCA? In this chapter, the findings obtained are presented in a rich, thick, detailed description that portrayed multiple perspectives about each participant of the study. The researcher provides a vivid and thorough portrait of each participant, as each participant reflected, revealed and shared his or her educational experiences. This chapter presents the findings of the interviews conducted with each participant, the document review and reflective memos which have been divided into three sections.

Section one presents each participant profile that was gathered through a brief questionnaire, open-ended interviews, document review and reflective memos. This section will enable readers to develop a unique sense of familiarity with each participant, as well as greater clarity and to enhance flow and readability of the analytic content. Section two presents and summarizes the main findings. Themes that emerged from the findings are organized into the following four categories: (1) SCA Pitfalls to Higher Education; (2) Resiliency: Living Through SCA; (3) The Challenges of SCA; and (4) Living with Uncertainties (SCA).

The findings that make up each of the category have been substantially and thoroughly rethought, reorganized, revised, rewritten into a well-developed and supported themes and subthemes. Every stratum of these thoughtfully framed themes is a fair representation of each participant’s views and perspectives. Every layer provides sufficient detail in such a manner that
allows readers to develop and make sense of the data that has been gathered. Thus, this provides a greater familiarity and understanding of who each participant is as a separate individual, but yet part of the same poignant picture and unique experiences. Section three presents the data of the findings, a review of documentary sources gathered and analyzed for the research, and a note about the use of the researcher’s reflective memos.

**Background for the Study**

This research examines the educational experiences of four people who are living with SCA. Participants were selected from the four regions of the United States: Northeastern (New England), Midwestern (East North Central), Southeastern (South Atlantic), and Western (Pacific Coast). Four people, one man and three women were interviewed for analysis. These individuals were selected based on a set of pre-defined characteristics (criterion sampling) and by word of mouth, asking family members and friends to assist to identify potential research participants (snowball sampling). The analysis that resulted from each personal narrative tells the story of the participant’s unique personal lives, personal experiences and their education experiences (retrospectively) as individuals living with SCA. This chapter presents the research findings of two structured open-ended telephone interviews. The first interview took approximately one hour and thirty minutes. The second interview took approximately twenty-five minutes to one hour. All interview responses were audio-recorded and later transcribed solely by the researcher. The interviewee’s responses were then color-coded and entered into a display of spreadsheet-like and table for later analysis.

In this chapter, a review of collected data through examination of documentary evidence provided by the participants was discussed. The documents consisted of a review of different
types of information and artifacts regarding the participant’s disability, medical issues, family, religion, faith and belief. Documents shared by the participants at the end of their interviews were aggregated with the interview data in order to facilitate analysis and comparisons among participants. The gathered documents reflect each participant’s social-emotional feelings, experiences and responses based on their past and/or present moment experiences with SCA. These documents also aided the research inquiry in its quest for meaning, social support and shared opinions. Additionally, to express and reveal further important insights into how SCA has influenced or helped shape participants educational experiences as persons living with SCA. Thus in essence, to enlighten the understanding of the researcher central question: What are the educational experiences of individual living with SCA?

It is very interesting to note that two of the participants keep specific artifacts in their possession for many years to be reminiscent of vivid moments and certain periods of their lives. Another participant recounts that she reads scriptures from the bible. She stated that there is a particular verse from the bible that offers words of encouragement, provides inspiration and strength as she continues to cope with SCA and life’s challenges. Demographic Profile of the Study Participants table 4.1 follows, along with detailed description of each individual, Meet the Participants. Participant’s Profiles (Meet the Participants) also include information specific to their education, occupation and family background.
Table 4.1

Demographic Profile of the Study Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Race</th>
<th>Ethnicity</th>
<th>Continent of Birth</th>
<th>Highest Level of Education</th>
<th>Type of Occupation</th>
<th>Marital Status</th>
<th>Number of Children</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anita Green</td>
<td>Female</td>
<td>56</td>
<td>Black</td>
<td>Afro Caribbean</td>
<td>South America</td>
<td>Bachelor’s Degree</td>
<td>Retired/Disabled</td>
<td>Divorced</td>
<td>1</td>
<td>Orisa/Yoruba Religion</td>
</tr>
<tr>
<td>Jeff Gray</td>
<td>Male</td>
<td>50+</td>
<td>Black</td>
<td>African American of West Indies</td>
<td>South America</td>
<td>Doctorate Degree</td>
<td>Therapist/Minister of Religion</td>
<td>Married</td>
<td>2</td>
<td>Seventh Day Adventist</td>
</tr>
<tr>
<td>Sarah White</td>
<td>Female</td>
<td>45</td>
<td>African</td>
<td>Yoruba</td>
<td>Africa</td>
<td>Bachelor’s Degree</td>
<td>Research</td>
<td>Married</td>
<td>2</td>
<td>Christian</td>
</tr>
<tr>
<td>Beth Brown</td>
<td>Female</td>
<td>52</td>
<td>Black</td>
<td>African American</td>
<td>North America</td>
<td>Associate’s Degree</td>
<td>Nurse</td>
<td>Divorced</td>
<td>2</td>
<td>Christian</td>
</tr>
</tbody>
</table>
Participant Profiles

The in-depth interviews generated information-rich data that provided unique insight into the participants’ stories about shared-SCA experiences and many common similarities, yet with differing perspectives. These differences will become clear from the extensive collection of quotations from the interviews which was used to support and further confirm the thematic stories that emerged from the participants. The trajectories of the stories that emerged in the analysis of the interviews became the subsequent perfusion of four themes that will be discussed in more detail in the sections that follows Meet the Participants.

Meet the Participants. Three of the four individuals interviewed for this research are foreign born naturalized American citizens. These three individuals received their primary and high school education outside of the United States in the countries of their birth, South America and Africa. Two of these three individuals received their higher education in the United States. One of the three individuals received her higher education in Africa. The fourth individual is a Black-American woman born, raised and educated in the United States. All four individuals remarked on the supportive and positive learning environment that they received from their teachers and professors. They emphasized that their teachers and professors had treated them fairly and respectfully concerning their scholastic experiences.

Pseudonym (code name) is assigned for each participant and used throughout to protect each participant’s identify; and to maintain the promise of confidentiality to each participant, that each participant will remain anonymous in the research to the public in the written result. To further maintain ethical principles of beneficence in a research study, the names of places and other identifying features have also been changed across the data to ensure confidentiality that
the data cannot be traced back to the participants. The following section reviews detailed individual profile of each participant.

**Anita Green.** Ms. Anita Green is a 56 year old woman of African heritage born in the Southern Caribbean. She was an only child and her father left the family when she was just a baby. She was very sickly as a child not understanding what the cause of her sickness was; she only knew she had limitations placed on her because if she did what other children did she would suffer a lot of pain. Her mother did not know the cause of the illness. Her doctors were also mystified; they told her parents she had inflammation in the bones and in the joints. Her mother did not learn of her Sickle Cell Anemia condition until Anita was about seven years of age. Anita’s mother then became very overprotective of her. She was not allowed to ride her bicycle or go out in the rainy season because of a fear of getting a chill which can bring on a sickle cell pain crisis. Even then she was in the hospital many weeks at a time and a few times a year. Her mother was told by the doctors that she would not live into her twenties and because of the lack of knowledge in those days by the doctors in South America, the treatment was almost unknown, it consisted only of bed rest, food and water intake.

Ms. Green came to the United States of America at the age of sixteen and then the treatment became better, she was given oxygen, pain medicine, and intravenous fluids and told to drink lots of water. Since she has became an adult she has been able to manage her crisis a little better. She can tell when a crisis is coming on and take medication for it, and if the pain gets unbearable, she can call for a ride to the hospital or an ambulance if she is not able to drive herself. The hospitals in her area now are much more able to treat the condition than before.
Often times, Anita only requires to be given oxygen, intravenous pain medication and when the crisis has subsided, sending her home without a need to be hospitalized.

Anita attended a prestigious university in the northeastern area of the United States (New England), but because of her mother’s illness, she had to drop out of school to take care of her. Later in adult life she resumed her education at two other impressive colleges in New England, graduating with a degree in Management and Marketing. Anita worked off and on before becoming completely disabled in 2005. Unfortunately, Anita’s Mother died about thirty years ago and she has not kept in contact with her father who lives in Europe; she has not seen him since the 80s. She has been married, but is now divorced with a grown son who does not have the illness, only carries the traits. She is a single woman living alone which she enjoys very much. She take pleasure in her solitude, enjoys her life, likes going out occasionally with friends, but if the occasion does not arise, she is satisfied and comfortable with her seclusion and being a loner.

Jeff Gray. Mr. Jeff Gray is a well educated man of African heritage in his fifties, born in northern South America, son of elementary educated mother and father. He remembers being in pain when he was a young child, but could not understand what was causing the pain. His parents were very aware of his crisis and would see that he received treatment, although they did not have a name for the condition and medicine was rather limited at that time. Jeff’s parents would help him in every way they could such as, keeping him from school when necessary, providing him with rest and proper food and water. Jeff was not diagnosed with SCA until he was seventeen or eighteen; he has a sister who also suffers with SCA. He moved to the Pacific Coast of the United States in his twenties, and because of his own desire to achieve and also
because of his father who was a tradesman who worked as a carpenter and a farmer who was also a well read man, even though, he only had a elementary education had instilled in his son the will to become educated beyond high school.

Jeff Gray realized at a young age because of the SCA it was imperative to be well educated in order to secure a white collar job versus a blue collar job which he deemed he would not be capable of handling because the physical stress could cause SCA crisis. In his adulthood, management of the disease has been phenomenal and successful which has enabled him to obtain a PhD and is very successful in his chosen profession. Jeff is a married man with three children (two adult boys and a teenage girl) who are very supportive and understanding of him. When in sickle cell pain crisis, his three children assists him getting in and out of the van, going to the doctors/hospital, they assist with his medications and so on. When necessary, his wife assists him getting a shower and just being there for him when he is in crisis.

**Sarah White.** Sarah is a black African, born in West Africa about forty five years ago. She has five siblings and only one beside herself has SCA. Her parents learned she had the disease at the age of three or four when three of the siblings came down with measles and they were taken to a doctor, blood test were taken and that is when it was discovered that Sarah and one of her sisters had SCA. Although, her mother always would give her very good food with high protein and folic acid and was very overprotective of Sarah and her sister, Sarah was not told she had SCA until she was off to college at the age of sixteen. The university she was going to attend was away from her hometown, out of the protection of her parents. Sarah’s parents realized she had to be told about her condition. Her parents located a clinic at the university, talked to the doctors there and had Sarah come in, and it was explained to her that she had SCA.
She was told what she had to do to care and protect herself from having too many sickle cell pain crises. Sarah had no idea what SCA even was, her mother explained it to her, then she was given a list of what to do and what not to do that might prolong the time between crisis attacks. Sarah explained that in Africa, a kind of stigma is attached to people that have the disease, it is thought of as something to be looked down upon.

Sarah White’s parents are well educated people, her father has a master’s degree in Animal Biology and Plant Science, and her mother was a high school teacher and a school administrator, yet they still hid the fact that Sarah and her sister had SCA. When Sarah was in college she did not inform any of her teachers that she had the disease unless compelled to because of too much absenteeism. She only confided to her closet friends that she had SCA. In fact, even though, she was invited to parties she would not attend most of the time because she was afraid that she might have a crisis and portray her illness to everything. Sarah is married and has two children, her daughter knows she has the disease and is very worried for her mother. Sarah’s daughter notices things about her mother, and if something is not quite right she worries and tries to help her as much as possible. Her son is too young to understand the reality of the illness. Sarah’s husband is very helpful and tries to take some of the responsibilities off her shoulders, like helping with preparing dinners, housework etc. Sarah and her family now reside in the South Atlantic region of the United States.

Beth Brown. Beth Brown is a Black American born in a smaller town in the East North Central region of the United States. She is fifty-two years old and the youngest of six children, she has five older brothers and Beth is the only child with SCA. Her parents learned that she had the disease when she was six months of age and Beth herself was told when she was five or six
years old. Beth’s parents separated when she was a baby; thus, she was raised by a single mother with only a high school education and her siblings. Her mother always saw that Beth obtained the best help that was available even moving their family to a larger city to have the benefits of a larger hospital. Beth's mother and brothers took exceptional care of her, she was by her own account spoiled because they would try to the best of their abilities to shield her from anything that they thought would cause a sickle cell pain crisis; being very overprotective as a result.

Ms. Brown’s siblings have varying degrees of education, three including herself have college degrees, one has a PhD and is a professor at a prestigious university, and the other three have a high school education. Beth has a college education and is a registered nurse who works with SCA patients. Beth now lives by herself in a small mid west town near her four brothers who still keep their eyes on her to help her in many ways. The brother with the PhD lives several hundred miles away. Beth’s mother who is now passed away was always in constant state of fear of Beth coming down with a crisis. If Beth feels a crisis coming on she calls one of her siblings and they will assist her during her crisis, taking her to the hospital, getting her medication for her and just being there for her. Although, Beth is no longer married, she has two adult children, a son and a daughter. Her daughter has a daughter of her own. It is not known at this time if Beth’s granddaughter is a carrier of SCA or not, but plans are to determine that at a later date. Beth hopes that the disease will die out in her family if no one is a carrier.

**Participant Profile Summary**

Participant profiles were presented in the order in which the participants were interviewed. The goal for each participant profile was to set the context for the interviews and to describe the overall quintessence of each person’s story; thereby, capturing the essence of their
experiences. Now that the stage is set with a descriptive vivid set of pictures for whom each participant; the following sections describe the themes based on participants perceptions, experiences and reactions to the research topic. Table 4.2 outlines the themes and the series of sub-themes that are central within each theme that will be discussed in this chapter.

Using the most appropriate and rigorous qualitative research design and methods for collecting data, this research has been able to answer a wide variety of questions related to educational experiences of individuals living with SCA. This research employed one of the models described by Lieblich et al. (1998) as a tool for analysis. Lieblich et al. (1998) narrative approach that was used focused on categorical-content analysis. Extracted themes from the transcript were further analyzed and then tapered down into four prominent themes, including sub-themes within each prominent theme. These themes are presented respectively: SCA Pitfalls to Higher Education; SCA and Individual Resiliency; The Challenges of SCA; and Living with Uncertainties (SCA). The following sections after table 4.2 discuss the themes and sub-themes in further details.

Table 4.2

Themes and Sub-Themes

<table>
<thead>
<tr>
<th>SCA Pitfalls to Higher Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>• SCA Interferes With Educational Experiences and Opportunities</td>
</tr>
<tr>
<td>• The Journey to Higher Education</td>
</tr>
<tr>
<td>• Balancing Academics and SCA</td>
</tr>
<tr>
<td>• Higher Education A Necessity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resiliency: Living Through SCA</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Building Resilience to Cope with SCA</td>
</tr>
<tr>
<td>• Family Support and SCA</td>
</tr>
<tr>
<td>• Spiritual-Religious Coping</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The Challenges of SCA</th>
</tr>
</thead>
<tbody>
<tr>
<td>• SCA and Stress</td>
</tr>
<tr>
<td>• The Emotional Impact of SCA on Family</td>
</tr>
</tbody>
</table>
SCA Pitfalls to Higher Education

The pursuit of higher education and academic aspirations are critical decisions fueled and heightened by SCA pitfalls. There are a variety of factors that influence a student’s decision to enroll in a college/university. It appears that the participants in this research are purpose-driven by either personal or family experiences in their pursuit of higher education. It is significant to note that influence of family and personal aspirations were the most significant factors that motivated each participant to pursue a higher education. Many things can cause a pitfall in the goal of higher education, such as lack of money, not enough teaching assistance, many absences from school, peer pressure, single mother (not enough time to assist students), and pressure to succeed as higher education is essential to anyone with SCA. The narratives in this category provide detailed examples to illustrate clearly some of the latent challenges and pitfalls that implicitly shaped the scholastic experiences of the research participants – as well as their vision and prospects for a higher education as individuals living with SCA.

SCA Interferes with Educational Experiences and Opportunities. The findings of this research provide strong evidence that SCA can affect the goals of learners. For example, Anita Green stated that sickle cell would always sabotage her progress in some way or the other. Jeff Gray stated that, “I don’t see SCA as in any way as different than any other challenge such as, if I had the flu or a broken leg.” Sarah White explained, “education wise sickle cell affected me a
lot because there are times when have I major tests, I will have exams and I’ll miss it. I’ve had exams brought, questions brought to me on the hospital bed just because I had a crisis during that time. So those experiences have been bad, you know regarding sickle, it cuts, it takes, when I was in college, it really took a lot of my time off school, I was in and out of hospital in my college days.”

Beth Brown stated that, “in elementary and middle school, there were times I needed additional help because I was out so much with pain crisis, I needed tutoring to help me stay up with the rest of the class.” The impact of SCA on individuals can vary to a great degree as the abovementioned examples suggest. SCA can marginalize the education of some individuals depending on their individual needs, tolerance and endurance. These are some of the obstacles and reasons that have been identified among individuals with SCA. The findings from this research provide strong evidence that SCA can limit and also interfere with opportunities towards higher education. Jeff Gray and Beth Brown asserted that we need to empower and encourage students who are living with SCA to take charge of their education and expand their vision of academic success beyond that of blue collar jobs. Beth Brown commented: Just Do It!

**The Journey to Higher Education.** Often, people who have disabilities in many cases, and empirically in the case of SCA are snubbed or dismissed as inept of accomplishing a task or job because they are not given the prospect to display their skill set; or to develop and/or to show their ability. Each participant’s viewpoint in this research is a representative example of the many of the significant societal and cultural barriers that people with disabilities face every day in or trying to achieve their full potential as persons with disabilities. Anita Green stated: “find strength whatever your talent is ….. letting those strength manifest.” Jeff Gray stated: just deal
with it …… I had to deal with it; it wasn’t seen as a barrier that would hold me back.” Although, Jeff Gray concluded that a white collar job verse a blue collar job is advantageous to individuals with SCA for many reasons.

Sarah White relayed that higher education was, “just a normal thing, they didn’t [parents] go over like really have to encourage me that, it was just a natural thing, I think it was the environment I grew up in, it was expected that everyone should after high school just go and obtain a bachelors that was the next thing, yeah.” Beth Brown stated: “it is definitely better for us to not have a blue collar job. It is definitely better for us to do a white collar job.” Beth Brown expressed further that we have to change the mindset of people with SCA. Beth Brown lamented, “what is going to get us to those white collar jobs is education, education will get us there, it is so easy, so grab that education and latch onto it.” All four participants in this research unequivocally agreed that a higher education is a must for people with SCA.

**Balancing Academics and SCA.** The data from this research provides significant evidence that navigating school, work and life is especially difficult for the three women when compared to Jeff Gray, the only male in the research study. For the three women, academic demands of school were intense like anyone else, but especially challenging for them because of extended efforts that was required to be at least equal with their peers in terms of scholastic achievements when going through the arduous process of learning. In telling their stories, all four participants described their experiences during their high school and college years, some shared positive experience with very good academic support from teachers, while others described struggles. Jeff Gray shared that there was a time when he was in graduate school in the midst of
doing a particular test and a research project; and he felt a sickle cell pain crisis coming on. Jeff Gray described:

I was able to get through the test, but when I approached for medical attention they were so slow and were not proactive or responsive so it evolved into a crisis, they had me in the hospital for 9 days and that had a very negative impact on my education, I recovered to get back on track, I managed to get through the course very well with no problem. I just had to reschedule and I was able to get everything in on time before the close of that particular quarter, so that was an experience that was very painful and very destructive to me.

Beth Brown sited many ways in which she had to balance SCA and her academics. Beth Brown recalled a particular time when she had just had a hip replaced and had to be out of school for so long. “When I had that hip replacement I was in school and it was very difficult to move about on crutches with a book bag. But I had to do what I had to do, yeah because I was determined.” Similarly for Sarah White, SCA also affected her academics a lot and those experiences were dire. Sarah stated that:

There are times when I have major tests, I will have exams and I’ll miss it. I’ve had exams brought, questions brought to me on the hospital bed just because I had a crisis during that time. Regarding sickle cell, it cuts, it takes, when I was in college, it really took a lot of my time off school, I was in and out of hospital in my college days which did affected me education wise.

Anita Green flourished quite well during her high school and college days. But during elementary school years, Anita Green noted that she was out of school a lot because she had just
moved back to her home country of birth which put a strain on her academic experiences. This move impacted Anita Green, she recounted:

Everybody just knew this was a sickly child …… there was no extension of work over there, you have to do your work, you have to do your Common Entrance and I remember because of my date of birth, I had two chances to do Common Entrance. I was in the hospital so much that my first chance in Common Entrance, I couldn’t catch up and when I did that exam, I failed and I had to go back to my elementary school for the following year because I had a second chance. So with the second chance is where I passed.

During their educational experiences study participants kept their health as first priority, yet strived to achieve a higher education with determination and will to carry on against all the odds. For instance, Jeff Gray’s introspective career exploration allowed him to stay motivated and dedicated. The evidence thus far suggests that maintaining a healthy balance between life and academic work is contingent on each individual’s ability to manage various aspects of their life. Findings from this research also suggest that attending a college/university can create additional stressors in the quality of life of a person living with SCA.

**Higher Education A Necessity.** The following quotations demonstrate some of the factors that were necessary to motivate participants in their endeavor for higher education. Higher education is perceived as extremely important to each participant in this research. Jeff Gray quoted, “my whole family was involved in school school school, that was the constant encouragement.” Jeff Gray said, “I grew up in, I was raised in a religious culture where academic pursuit was like part of the religion, it was constantly encouraged, you have to get your
education, they saw that, their interpretation or I should say their feeling was that this was a biblical mandate, a logical, a religious requirement to do everything you can to be successful.”

Sarah White indicated that her self determination coupled with her parents’ education beyond high school were salient, which in turn framed her need for a higher education; thus, allowed her to stay focused and dedicated on her educational aspirations:

What helped me was a personal determination ….. I just wanted to be a reference point that even with this disease you can achieve, and become somebody in life, so I think personally I had to like speak to myself and say that this will earn me respect, yes from people, so that one really influenced me. My parents were a great encouragement too, they allowed me to become whatever I wanted to become and they let me know they will be there to support me all through.

For Beth Brown, obtaining a college education was a combination of several factors. For her, it was the combination of her teachers, her mother, her brothers and the confidence they each had in her, coupled with her fierce will and determination to succeed. At an early age, Beth Brown knew what she wanted to do; she knew she wanted to become a nurse. Beth Brown shared that:

I wanted to do this, this is what I was meant to do and be ….. mainly because of sickle cell and the type of treatments that I encountered, the type of nurses that I encountered, it wasn’t positive, we were profiled because of sickle cell, all of these things, profiled…… I wanted to get in there and change things, to change the things, not the running around of taking care of people, but I wanted to change the thinking, the crazy thinking of nurses, they were ignorant, yeah.
Beth Brown also shared that obtaining a college education was a necessity for her because:

It was something that I jumped on since I was a little girl that I wanted to do and I had to do it. I had to prove that I can do it, that I had to do it because I wasn’t supposed to live past a certain age. For a few reasons, I wanted to prove that yes I can do this despite my being sick, despite the fact that I’m not even supposed to be here, despite all these things I’m going to do this.

Anita Green shared some of the biggest factors that enabled and motivated her to complete her bachelor’s degree after many years of being away from school. Anita Green reflected, “I think knowing that at some point in time I would have to stop working. I spent a lot of times in and out of the hospital; um it wasn’t easy to hold down any particular job. So for me I just wanted to accomplish that, to accomplish and complete at least one degree or the other.”

The narratives illustrate that higher education is perceived as extremely important to the participants in this research, and a necessary ticket to good jobs. Each participant believes that placing higher values on a college education and upward mobility is important especially for persons with disabilities, and as one possible way to overcome some of the barriers that are associated with SCA.

**Resiliency: Living Through SCA**

This category captures the delicate and critical essence of resiliency, courage, the emotional strength and the benediction bestowed by each participant by their commitment and by their anchored dedication to this phenomenon of interest. Participants described the influence and effects of SCA on everyday life. In listening to their narratives, hearing their personal stories, it quickly became noticeable that all four participants have experienced profound
similarities and uniqueness’s. The findings of this research revealed that resiliency plays a role in the quality of life of each participant. All four participants have unique qualities, strengths, and skills that enable them to adapt to SCA-related stressors and challenges. Though each participant is affected similarly by the disease, their experiences and feelings are different. Based upon each participant’s answer to the question about how they cope and thrive in the midst of the many SCA-related challenges and stressors, participants noted that they do not necessarily follow any particular pattern of coping strategies. Developing resiliency is a personal journey. People do not all react the same to traumatic and stressful life events. An approach to building resiliency that works for one person might not work for another.

**Building Resilience to Cope with SCA.** The findings of this research show that painful episodes are devastating for the individuals who experience its affliction because it influences and affects quality of life. For example, Anita Green recounted, “I think I did it all on my own. Yeah, I did a lot of my own coping mechanism and just did it on my own.” Anita Green built resilience to cope with SCA before coming to the United States as a young person because she had no information about SCA. She narrated:

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...... because of the lack of education about sickle cell there was no help, no helping in my ability to cope. I just had to develop my own coping mechanism knowing that I continued on with my life with limitations as best as possible and when I ended up in a crisis, I had to be hospitalized and at that time the family was there.
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In places in the interview Jeff Gray indicated that he was able to manage SCA so well. He stated, “in my academic life particularly high school right on to the graduate school and I mean I had crisis, but it wouldn’t affect schooling, but the more severe crisis may go a little
longer, but after that I just managed it, so for me, it was a very annoying interruption, but it
didn’t color my education, where I was limited because of the sickle cell.” Jeff Gray also stated,
“I would try to work through it, I think I probably shouldn’t have because that would have made
my academic experience a little more better where I would say well, let me get well, but I
wasn’t, my whole mentality was one in which I said let me just get through this.”

For Sarah White her teachers played a really important role by minimizing stressful
situations which enabled her to cultivate resilience and to focus on her education rather than the
stressful situations. Sarah White spoke with sadness has she recalled a time when she had to take
an examination in the hospital. She said, “education-wise, sickle cell affected me a lot because
there are times when have major tests, I will have exams and I’ll miss it. I’ve had exams brought,
questions brought to me on the hospital bed just because I had a crisis during that time.” Sarah
White further recalled that her college professors did not place too much stress on her, she
recounted, “they gave me leverage when I had to turn in assignments late, they allowed it, yes.”
Each of these experiences helped Sarah White to build the resilience to cope with SCA.

In a similar vein, Beth Brown expressed, “sickle cell has affected my education in many
ways, I can’t say I have had a normal experience, it was always assistance that I needed because
I was out so much …… from being sick and it could have slowed me down, it could have, yeah,
but it didn’t.” Beth Brown was also able to build resilience to cope with SCA because of the help
she received from her doctors and teachers, she shared:

I remember this particular time, I remember a specific time that I got sick during finals
and I was in nursing school, I was taking anatomy and physiology, I had finals and um I
got sick, …….. so my doctors contacted the professors …….. and they were able to
schedule my exam at a later date, they were trying to make me take the exam in the hospital and they couldn’t allow that ……, but they allowed me to take it at a later date and these were things that were really helpful, they helped me so much.

Beth Brown stated that she wanted to become a nurse mainly because of the type of treatments that she had encountered in hospitals. She wanted to change the ways SCA patients were being viewed by healthcare professionals. As a patient, Beth Brown believes that the majority of nurses profile SCA patients in hospitals. Therefore, she wanted to become a nurse to change the “the crazy thinking of nurses who were ignorant,” of the dilemma that SCA patients encounter when they are in a SCA crisis in the emergency room. Beth Brown stated:

Yes, it was mainly because of sickle cell and the type of treatments that I encountered, the type of nurses that I encountered, it wasn’t positive, we were profiled because of sickle cell, all of these things, profiled. The negative ways you being sick, you being sick in the emergency room and you are profiled, you are racially profiled for being sick, they look at you like you are a drug seeker. Those things really caused me to become a nurse. I wanted to get in there and change things, to change the things not the running around of taking care of people, but I wanted to change the thinking, the crazy thinking of nurses, they were ignorant, yeah.

Beth Brown asserted that while she was a student many years ago, her healthcare professionals treated her extremely well and were supportive; although, some of the younger nurses treated her as a potential drug seeker. The older nurses and doctors went above and beyond, treated her respectfully, and have learned that not all people requesting analgesics are drug seekers; they are in fact in need of medication to reduce their SCA pain crisis. For instance,
her doctors and nurses attempted to convince her college professors to allow her to take her examinations in the hospital environment as she was suffering from a sickle cell pain crisis at the time the test was being given. This was not permitted of course, as a test or an examination must be taken under the school’s supervision. Upon Beth’s return to school, her professors administered the test to enable her to keep abreast of her classmates. She stated that they were sympathetic and underscored how wonderful they had been throughout her educational experiences.

Participants in this study described how they were able to build resilience to cope with SCA and not to become discouraged, rather each of them were filled with optimism, enthusiasm and hope. Even though, no-one can be resilient all of the time and there is no way to conceptualize resilience or how it can measured; nevertheless, the findings in this research indicate that strengthening the resilience to cope with SCA is beneficial in the educational process of the individual.

**Family Support and SCA.** Family involvement and support in the care management of the study participants plays a huge role towards fostering the ability to cope with SCA. Each participant expressed that they find comfort and strength through their family members when in the midst of a sickle cell pain crisis. For each research participant, their family’s active support continues to heighten their view of life. Anita Green’s family supported her by looking after her son for four years from the age of 3 to 7 as Anita was not capable of nurturing her son because of her severe sickle cell anemia condition. Anita Green stated, “I sent my son home to my family for 4 years. I brought him back when he was 7. I sent him home when he was 3 going on 4 and brought him back when he was seven.” Anita Green relayed that whenever she is sick, she
relishes the support given by her family, their support gives her the courage and strength to cope and deal with SCA.

Jeff Gray’s family supported him, “they never thought that this illness should stop me from accomplishing anything, you just have to go along with it. I think that the attitude that they had was central, may have been central to my coping in that their attitude was this was nothing basically, you still can succeed, you still can achieve, and you still need to do what you have to do to get by.” Jeff Gray’s family was always very encouraging, most especially his father, his father motivated and empowered him throughout his academic years. His family’s unyielding support and unwavering zeal helped him plow through his studies among the many difficulties and complexities of SCA. He gleefully noted:

I think it is the idea that or the fact that no one in my immediate family ever suggested that I couldn’t become what I wanted to be even as a person with sickle cell. My immediate family never suggested ……, they never suggested that sickle cell was a limiting factor; and they always thought I could become anything I wanted to become.

Sarah White embraced the support of her family. She explained that the support she has received helped her to manage and to overcome the difficulties of SCA. Sarah explained further that: “the support is so important,” to her ability to cope well which gives her encouragement.

Beth Brown’s mother and her involvement helped her tremendously. Beth Brown remembered when she was a teenager, “when I was young I remembered her [my mother] being very interested and wanting to know everything, why do I have it? Where did it come from? All these things, so I got involved in sickle cell disease, I wanted to become a nurse, you know, it
helped a lot. It helped a lot.” Beth Brown mother and her 5 brothers were very helpful and encouraging. She stated:

……it means everything to me that I have their support. It has meant everything to me, it has meant the difference in the life that I have lived, you know, I can’t even put it in words, really, yeah. Yeah, they are the reason why I’ve never allowed this illness to stop me from just giving up. You know, it’s easy to just give up when you have an illness, it’s very easy to do that you know, yeah.

Being a family member of someone who has SCA can be an overwhelming chore, but their love and support is crucial to the well-being and a must in order to have a fruitful and academically successful life. Thus, family relationships can give an individual the ability to build resilience and the need to cope easier.

**Spiritual-Religious Coping.** It was apparent from the study that faith, religion, and its affective reactions are a concrete source of support for the participants. Spirituality and religion are a source of coping strategies for Sarah White and Jeff Gray. These participants lean on religion as a support to cope with SCA. While, Anita Green did not mention religion or spirituality as a source of coping, Beth Brown’s journey with SCA has been helped with her faith, “faith through God, faith through God. Through God, yes.” Beth Brown describes herself as a spiritual person who is “strong, confident and hopeful” through her faith in God.

The bible seemed to be a very prominent theme in Sarah White’s life; she uses her faith as a tool to cope with SCA. When she shared her understanding of SCA, she uses quotes from the bible and scriptures to help cope with SCA. Sarah White revealed her inner thoughts, “I overcome my fear with the word of God really because the word of God it leads me on and keeps
me that I would not die with this disease, I would live.” Sarah White uses the word of God to speak positive in her life each morning and with every situation that arises. She cheerfully conveyed:

I have a scripture, you know that I use, I have scriptures not even one, different scriptures that I use that motivates me, encourages me, every time the fear tries to pick I use the word of God to counteract it, you know, and I choose what to believe, what medical science says about this disease, but believing what the word of God says about it, I would live, I would not die, I would declare the word of the Lord in the land of the living. I use so many scriptures like that, that I can do all things through Christ who strengthens me; I just motivate myself through scriptures, so it helps me so much.

Sarah White’s Christian foundation is what she has based her life on, her Christian foundation is what she believes has supported her all her life and continues to carry her through each and every day. She passionately expressed how she copes with SCA through her religious devotion:

There is this particular verse of scripture in the bible from the book of Philippians chapter 4, verse 13 and it says: I can do all things through Christ which strengthens me. Which means there’s nothing any other person in this world can do, any other person not living with this disease, any normal healthy person can do that I cannot do, I can do everything I choose or want to through Christ, just by putting my trust in Christ who strengthens me, which means physically, emotionally and all that, it strengthens me to achieve, achieve whatever I want to do in life, so that’s what I base my life upon, and it’s been carrying me on and I know I can actually do all things really, everything, everything I want to become I can become through Christ. So that’s it really, that’s me. The key thing that has
seen me through, seen me through my education, my family life, my ability to not just have one child, but to have two children, have a good family life, you know, to still have a husband and those are all the support, yeah. I see myself as normal really, right now, I see myself as normal and happy, yes because of the word of God, so that’s it.

The influence of religion is perceived as a coping strategy for Jeff Gray. Jeff Gray, a pastor, receives inspiration from his faith and a belief in a higher being. Jeff Gray’s religious experience taught him that he can achieve anything in Christ. He also pointed out that his faith guides him, “I have been able to manage my life in a way that is very positive …… my immediate family, my church and the community, my friends around me and my relationship with God, so there are certain things that I don’t do.” Pastor Gray’s church life and his strong personal faith are inspired by, “I look at spiritual props about me, religious literatures and so on and I think that those are sources of inspiration.”

**The Challenges of SCA**

Sickle cell anemia is characterized by many dramatic circumstances, challenges, difficulties and changes. It impacts all areas of life such as, health, family, relationships, friendships, economic well-being, education and future endeavors; to all intents and purposes, it mars quality of life even basic living skills. Parents and family members bear most of the consequences and it affects every facet of their lives also, especially the family structure and its dynamics. In addition to the active role that parents and family members play in the health management of a person with SCA, they also play a pivotal role in their education.

Research participants noted that their parents greatly influenced their educational aspiration and outcome. For instance, Jeff Gray’s father offered tangible advice that significantly
benefited his learning experience; and in turn, helped to boost his educational and career promise. Sarah White’s father and mother not only motivated her to achieve her educational aspirations, but they also assisted her to reach her goals. Beth Brown’s mother moved her whole family to a larger city to accommodate Beth’s sickle cell anemia health needs. Anita Green’s mother brought Anita to the United States to secure advanced treatment centers and better educational opportunities for Anita. The parental encouragement and support that participant’s parents supplied help to propel each of the participants to realize his or her scholastic dream. The indispensable supports instilled confidence that helped each participant to act upon his or her desire for higher learning, higher career aspirations and beyond.

**SCA and Stress.** Findings indicate that the severity of stress depends on the participant’s ability to effectively cope with a variety of stressful events, situations and circumstances. Findings suggest that coping with stress is dependent on the individual, his/her resilience and intrinsic coping strategies and skills. Sarah White uses a range of strategies to deal with her stressors. One of these strategies is, “well it is a condition in which you really have to sit down to understand myself which actually to a large extent I have understood myself.” Another of her strategy is to, “I know my do’s and don’ts, I know how to trigger a crisis, and I know how not to. Although, sometimes it is completely beyond my power, but I just try as much as possible to be very safe and lead a stress less life.”

Jeff Gray deals with stress in a very different way. He states that “be attentive to your health ……. be conscious of your limitations, the limitations should be there to guide you, they are serving as guide post to help you, to help you function, not as things to be used as restrictions, to be interpreted as restrictions, but has guiding posts.” Another quote of Jeff Gray,
“I try to manage it, but the truth is that I think am careful a lot, I try to be careful in what I do, what schedule I can keep, and so on, that’s probably how I manage it.” Jeff Gray also stated that, “I think particularly sickle cell has an impact on my life, it is a limiting factor that is going to be there in some ways, I probably can go so far and probably can do so much.”

Anita Green manages SCA and stress to the best of her ability, she stated that:

It really wasn’t easy at all. Stress adds a lot more, and I try to avoid stress as much as possible. This life is so stressful already. In general I just try to avoid additional stress. When I was in school, I would study hard as I could; you know really turning good papers. I was on the dean’s list every semester. I did well academically once am not sick, I can do really well, so I focused on being the best I could be in my work and knowing that when I’m sick I’m sick and deal with recovering and recuperating from a crisis as best as possible.

Anita Green emphasized that she manages stress by being mindful of what causes stressful conditions for her, she stated, “I cope with pain, I manage it, I try to manage it as best as possible, I know what I need to do, if am in pain and I get on the oxygen, I take my pain medication, I try to drink a lot of fluids and I cope, I try to cope with whatever stress am dealing with at the time……, hoping that …. it doesn’t become too much that I go into crisis.”

In Beth Brown’s educational experiences, she noted that when she was in school, “she was still learning how to deal with SCA and Stress. Beth Brown acknowledged she was, “I don’t think I ever learned nor, I’m still trying to learn how to really deal with stress without allowing it to affect me because I have always allowed it to get in the way at times, but it never, it never stopped me, I was able to deal with it, but it caused me you know, going into the hospital.” Each participant’s strategy consisted of attempts to directly prevent stress by identifying the source
and the cause, both physically and emotionally. A variety of themes emerged during this research; participants shared some of the same difficulties, although at varying levels.

**The Emotional Impact of SCA on Family.** The findings suggest that SCA can be overwhelming for family members and can negatively affect the family structure. The findings also suggest that SCA has a detrimental effect on quality of life of the participants and can also place a burden, stress and strain on the family. For example, Anita Green related that she was an only child and her son also was an only child, and because of her frequent hospitalizations and her son being watched by neighbors and friends, he became very introverted. Anita Green sorrowfully disclosed:

He was an only child, he was very introverted and I couldn’t get him to really talk a lot, even when I asked him questions about how he felt, about having to go by the neighbor, he just did what he had to do or was guided to do, this was what he was supposed to do, mommy is in pain, mommy is sick; you go over to the neighbor’s house while she goes to the hospital. So to this day I don’t know how that affected him, but for me, I know that was just very traumatic and very stressful.

Anita Green raised her child has a single mother because of her and her husband’s separation, which was likely caused by her many crises. Anita Green expressed, “I wouldn’t say he [my husband] helped me to cope with sickle cell at all because the stress of marriage probably had me going into more crises. Yeah.”

Jeff Gray recognizes that the impact of SCA inherently affect his children. He explained, “[SCA] it intrinsically affects my children and they are aware that they are potential carriers of
the disease. They [my children] realize they have to maintain that awareness in their interactions, so they have to adjust.”

Sarah White emphasized that SCA does have an impact on her family structure, she said, “it does have an impact, a great impact on my own nuclear family.” She further stated:

Um, it does affect my [teenage] daughter, for a long time, she was actually very very angry at first when she heard [that I heard SCA]. It really really affected her.” My son doesn’t know anything, but my daughter anytime she sees me like even looking funny, it really affects her, she gets like scared and like what is happening to you mom? There were times she would be weepy thinking about it, so it affects her, but my husband, if it affects him, he doesn’t show it, I guess because he is a man of faith so he doesn’t show it. The impact of SCA affects Sarah White’s parents and her siblings. It is important to note that one of her sisters is also affected the disease. Sarah White explained:

Anytime they get a phone call from me like any off time, they know my set regimens, I should be sleeping at this moment so for whatever reason if I’m not asleep during the night or at any odd time and I call them, they all get so startled, what’s happening to her? Sometime if they try to get me on the phone and they can’t get me, they call everybody around me here. They start calling my husband, what is wrong with her? We can’t reach her, they are on edge about me, you know, it’s like very very sensitive, yes, they are very concerned, so even if I’m sick, any minor illness it is like you go to the hospital, even with any illness like minor illness that I can manage myself, they keep on insisting that I should go to the hospital and things like that.
Beth Brown described how SCA has affected her mother and siblings, as well as her own nuclear family. Beth Brown shared:

My mother she is passed now, but she was always in a state of fear of me getting sick, Beth don’t do this, don’t do that, and don’t go about this. And it does on my brothers’ fear of me not being sick. I have to say that it’s true that it pours down to my children, fearful of me becoming sick. It did affect my family structure because there is a lot of focus on me, so I’m sure as a child, my siblings, my brothers became tired of it in some ways you know. So it did affect the structure in many ways because not only because I’m the baby or the only girl, I have sickle cell. I was curdled and protected and all those things, you know.

Beth Brown shared an emotionally experience of how SCA affected her daughter’s stability when she was in eighth grade:

I never forget one day my daughter came home from school and she was very sad, I could see it in her eyes. So I asked what was wrong, and she told me that the teacher told her that people with sickle cell die at an early age. It really made me upset that she would cry and all that and I comforted her and I told her that the future, no one can determine when I’m going to leave here and that am not. Ultimately she felt better about it. You know, I just remember times like that. I think my kids were fearful of me becoming sick.

The findings of this research eminently suggests that parents and other family members play a critical role in the ability to cope with SCA, emotional functioning, the ability to participate in daily life activities and educational endeavors.
A Burden Shared and A Journey Shared. SCA is a family burden and problem. Caring for a family member with SCA can place heavy burdens and significant high levels of stress on family members. When a SCA patient is experiencing SCA pain crisis, everyone in the family suffers the incessant stress, strain, fatigue, and the burdens caused by the illness. The findings of this research provide a unique view of the role that family members play in the life of all four participants. This research indicates that the family members of all participants are more resilient as a result of their coping with the illness. These families see it as an equal sharing of family responsibility – a shared family burden.

The findings of this research suggest that the ability of the family to share the burden can result in a sense of empowerment for the person suffering from the condition. For example, Beth Brown’s mother relocated her family for the benefit of her daughter, Beth. Beth Brown remembered, “mother even moved, she moved from this small town…… which is a bigger city, with her six children because she knew that it would be better for me in terms of hospital care.” Beth’s brothers shared much of the responsibility, assuming some of the burden placed on Beth’s mother. Beth shared about her brothers, “um, they would, they would be around me, they would be my beck and call whatever I need, they would get it for me, um, I’m telling you I was just very spoiled. They really really, my brothers always showed me so much love and protection and all of that. They were always there for me, always there for me. They made sure that I didn’t get sick and when I did, they were there, always there.”

As a child, Sarah White’s parents bear the burden of her illness, as well as that of her sister who also has the disease. As noted by Sarah White:
As soon as the crisis starts, what she [my mother] would first do because normally it would start, I don’t know why sickle cell is like that, with me it starts in the night time, that’s when it starts, so at night time, the first thing I do is I go to her room, knock and tell her that I’m having pain, the first thing she would do is immediately boil water and start massaging hot towels on me on the affected area and then she will give me Panadol. She just tries to manage it ‘til day break, then as soon as it’s very early, my father takes me immediately to the hospital and I get admitted with drips from getting dehydrated and all that too.

Sarah White noted that both her parents always took their responsibility towards her and her sister very seriously and always responding immediately to a crisis. With pride Sarah related, “they don’t joke with hospital, they never joked with hospital care for me. There was even a time my father, I had to get blood transfusion, I think I was 17 years old and my father had to like because we have the same blood type, he gave his own blood for me, they said he had to like give me blood and he did.”

Anita Green explained that when she came to the United States as a child of sixteen, she realized then that a tremendous burden was placed on her family back home when the doctors explained that she would not live into her twenties. With great sadness she recalled:

At the age of sixteen when I came here when I started seeing a doctor here and I told him that you know the doctors back home said that I wouldn’t live into my twenties. A few years after that I remember him telling me, he said, I am not going to tell you that you gonna die, but what I would tell you is if you survive sickle cell at a later age you will have other complications. Probably lung failure, some other disease and what not.
Anita Green and her family were placed under emotional and psychological burden; she remembers it meant she and her family were always aware of her mortality. She emotionally explained:

For me it meant always being aware. For me it meant that I was a sickly child, I was always in and out of the hospital. For me it meant I wasn’t sure if I had a future. For me it meant because my family called the doctors because the doctors told my family that I would not live into my twenties, for me it meant getting stressed, it meant overcoming the fear that I would not live longer than that because I like life even though most of that life was spent in the hospital. Growing up as a child was not easy, but the majority of it up until the age of sixteen when I went to the United States, the majority of my life was in the hospital.

Jeff Gray reflected on his experience as a teenager and the distress SCA placed on him and his parents. The burden on Jeff’s parents was multiplied as Jeff’s sister also has SCA. This meant his parents had to careful nurture and give more attention to not one, but two children with this disease and yet, have time to nurture their remaining non-SCA children. Jeff Gray described, “they [my parents] used to be very distressed that I wouldn’t eat you know those kinds of things, but they did what they knew as parents to help. They were very helpful.” Jeff Gray also explained that his parents were very concerned and caring of his condition. He noted, “they are always supportive, my family is very understanding, very supportive, very aware and they would be very encouraging you know, when I get a crisis they would make sure and see to it that I get treatment.”
The findings highlight the shared burden, the shared journey and the enormous responsibilities placed on the families of the research participants. Each family had to cater to the individual needs of their SCA children while attempting to accumulate resources to provide a college education which they knew they would need in their adult life to sustain themselves.

**Living with Uncertainties (SCA)**

Some experiences can affect a person’s outlook on life and can influence the vision of their own life’s dreams and objectives. With a disease such as SCA, it can make uncertainties in life; although, each of the research participants have discovered ways and means to manage their difficulties and challenges. Each challenging situation is a stumbling block, yet they push their way through, by finding ways to counterbalance some of the difficult obstacles that SCA has placed on their life. Living with SCA causes uncertainties that touch every aspect of life; it is in and of itself, fear of the unknown. The following sub-themes describe the nature of each participant’s experiences in regard to social life and quality of life.

**SCA and Social Life.** Anita Green, Jeff Gray, Sarah White and Beth Brown shared the importance of maintaining strong and healthy relationships with family members and close friends. For each participant, it is a vital component of their wellbeing that enables them to thrive in the midst of all the SCA difficulties and challenges. Additionally, each research participant explained that family relationships and social support systems help them towards a healthy wholesome life beyond SCA. For each participant, family members and a few close friends are especially helpful in offering social, emotional, psychological and spiritual support.

Anita Green tried to function as a typical student, going to her classes, trying to be as normal as possible, but she also knew there were limitations, she could not play sports, and she
could not participate in normal student activities that involved any physical stress, so she refrained from those things. Anita stated: “as a child it did affect me because there was lots of limitations, um I couldn’t go outside or be outside with the children in the neighborhood. Um, I was pretty much secluded.” Anita Green further reiterated, “there were certain events that the school will have and my family wouldn’t send me to those events. So that for me was you know, I felt um, many a times I was saddened about not being able to go out and hang out with friends.”

Anita Green noted that now as an adult, the support from a few close friends and neighbors are important as she as a group of people that she can depend on for emergencies.

When Sarah White was in elementary and secondary school, she was excluded from many activities in the school and outside of the school because of SCA. She stated: “Anytime I went swimming I would always have a crisis during the night and also I was excluded from participating in sporting activity in high school and I was always kept in the class looking through the window wondering why I was not allowed to join the rest of my classmates.” When Sarah White was in college she experienced loneliness, unhappiness and withdrawal because of SCA limitations and the ways in which she was treated by her peers because of SCA. She sadly expressed:

My social life wasn’t too much great, socializing with them wasn’t, I try to, I sort of lived a lonely, not too much existence when I was in college because there were limits to the things I could do and so it made me like you know, don’t waste my time. The ones that embraced me were the few ones that I had trust and confidence in that I could share with, because it was very personal to me. Some of the ones I told, when I told them, um, some made fun of me really, yes. So which made me now to even not want to tell anybody, in
fact, I will only say that it is only in the past how many years now, like eight years that I just started, I won’t even say eight years, I will say six years now that I just started telling people about it like openly about it.

Sarah White now has a good spousal support which she says is a blessing to be able to depend on him.

Sarah White stated that she would like teachers to be more aware and sensitive towards people affected by SCA in the United States, and to educate peers of the students living with SCA of the disease and its impact on their somatic ability to function as students without SCA. Sarah White would like to see teachers of SCA students have discussions about the illness because it is not a disease that is common among the majority of the American children. Sarah White stated:

So once they don’t ostracize the children or bully them or cause any, so they should be made aware, have talks, be more open about it, let them know that this is a disease that is common with blacks. Um I don’t know whether the Caucasians have it, it is more with the Africans, African-Americans, so let them just know what it’s about. Quite a number of children don’t even know about sickle cell anemia, so they need to make all aware of it and just to be a support to whoever is living with this disease in their classrooms or the schools.

Sarah White would like to see a program developed to teach children in younger grades to be respectful and have empathy for people with disabilities. She would also like to see schools that have SCA students be made aware of the condition similar to Anita Green’s sentiment and Jeff Gray’s statement.
Jeff Gray’s ability to develop relationships when he was in school is notable when compared to the other research participants. He briskly noted, “I’ve always had exceptional social relationship with friends, some of my relationships developed from high school and I still maintain some of them in college, my college friendships were much more sustaining ones in graduate school.” He continued:

It [SCA] didn’t affect my ability to fit in at school. It’s going to come to, come down to who you get, you know, if you associate with people you can’t fit in with, it’s going to be a problem in being able to socialize and socializing is painful when that happens. For some reason even as a teenager, I wasn’t drinking and smoking, so I had to be careful, whatever forced me to be careful helped me along the way in managing sickle cell and managing overall life experience.

Jeff Gray’s well-honed social abilities, as well as his wife and three children’s support have allowed him room to maintain his professional life, as well as his family and social life.

Beth Brown’s lack of ability to join other students and friends in sporting activities seriously affected her school social life: “Yes. Well it really affected me, okay. That was this softball team that I wanted to join, friends joined it and I couldn’t really join because my lack of ability to run like that you know without collapsing. I couldn’t, I couldn’t do it. Swimming, sports, I couldn’t do it. I would be sick just all the time if I swim, you know.” Beth Brown believed she was athletically inclined, she was a tall girl and wanted to run track, but because of her condition she knew she would collapse which precluded her from fulfilling one of her dreams. She remembered, “I couldn’t go out for the track team and I’m tall. I’m a tall person. But I always liked run, but I was never able to play in sports. There were questions like what is
wrong with you Beth? But I couldn’t do it, I couldn’t do it.” Beth Brown conveyed that the support of her children and her five brothers have been a very important and valuable factor in her adult life. For each research participant, supportive family was a very important aspect for them during childhood and also now in adult life; friends that were gained now in adult life are crucial to their happiness and welfare.

**A Secluded Life Echoes Solitude.** The life of a person with SCA can mean living one’s life in the unknown with a future that is uncertain. For Anita Green, Jeff Gray, Sarah White and Beth Brown living with SCA brings a number of challenges, but one faction that is particularly challenging is coping with seclusion. Each participant expressed their dejectedness, but never felt defeated. Their inability to do certain simple things that they wanted to do, such as swimming, running, bicycling and et cetera caused some of the participants to feel rejection and dejection.

While Jeff Gray did not express any feelings of loneliness or solitude, the other three participants acknowledged that they did. Anita Green loves to be alone; however, she stated that she does not have a lot of friends by her own choosing, but she has the ability to socialize with friends whenever she so desires. She stated, “I don’t have a lot of friends….., I like to be home alone….. Yeah, love being a loner……. I am a loner, I love seclusion, I like being by myself, I go out and I socialize with friends when I feel when I want to be out there, but I’m comfortable.” Anita drives herself to the hospital if able, if in too much pain, she calls the ambulance without bothering any of her friends or neighbors. Anita stated:

I got so used to being by myself that you know I knew the routine, I knew pain, if I try to control it at home and it didn’t work, I just call the ambulance or sometimes I get in the car and I drive to the hospital myself and just do what I need to do without actually
bothering anybody. I do that a lot and as I get older it’s even worse. I do that a lot, the
independency of having you know being a person with sickle cell disease, but yet not
having a lot of family around and not having a lot of friends as just put me in that
direction to just be independent and do what I need to do. Yeah.

Sarah White lived a secluded life during her college years, she tried to fit in with the
other students, for example going to parties, drinking little wine with friends, but discovering
that her illness prevented her from doing too much and aspiring like the rest of the students in
social activities. Sarah reluctantly shared, “I never had a social life … I was afraid yes to
embarrass myself, yes .... It just made me to become a loner somehow … A loner because of
shame.” Sarah White also shared that there were days she would stay in bed all day hiding from
the world:

I tried to be normal like the rest of the gang of my friends, we go to parties, I loved to go
with them, but there were sometimes I just get sick after not sleeping enough hours. I get
sick from going to a party overnight and whereas they move on with their lives and I get
sick from it, so there were so many things that I will just not do. Everybody just did their
own thing and I was just left alone in the room in college because I wouldn’t want to do
what they do and now get sick. So I just stayed alone, so it just made me to become a
loner somehow, you know. So weekends I never had a social life, I’ll just lock up myself
in my room, we were two to a room and my roommate will go off partying and all that
and I’ll be there sleeping, you know just by myself reading novels, yeah.

For Beth Brown she stated that she never really felt lonely, she may have felt secluded at
times, but she had her moments when no one really understood her as they did not understood
what she went through on a daily basis. She sour fully recalled, “seclusion, I think there are times I may have felt secluded, but not to the extent of feeling lonely. I’ve never really felt that.” Beth Brown said softly:

Let me tell you, I used to, I used to say things um to guard, to guard against me being rejected because I’ve always felt no one would want to be with a person like myself, I have always felt that because it’s hard, it’s hard been, it’s hard to be with someone who is sick. It is not an easy thing, it is not an easy thing, I will be the first to admit that, but um, I wasn’t able to, no one, let me say this again, rejection has always been one of those things that I felt that um, that um is just like it’s simply the opposite of someone being accepted, whatever they choose that is their choice, it is okay with me, that is how have always felt, it’s fine, it is just like I like apple juice, you like orange juice you know, so have always felt to look at it like that.

The findings of this research show that one participant had no secluded life or loneliness during academic years, but for the other three, a secluded and lonely existence was mostly the norm.

**SCA and Quality of Life.** SCA produces many difficult and unexpected challenges that may greatly affect quality of life of individuals living with this disease. The following excerpts feature how each research participant adapt, cope and deal with the ever-changing kaleidoscope of life’s tides. Sarah White always has to consider SCA before she makes any career choices or future plans and decision in her life. She felt very limited in what activities and career choices she could make for herself because of the many times she has been hospitalized with major crises. She knows her limitations and sometimes tries to go beyond her expectations. She stated:
Um, I don’t like it, it limits me in so many things. There are other career options that I would have loved to go into that sickle cell anemia limits me from doing. So many activities I would have loved to be involved in, I can’t because sickle cell is the first consideration and even if I want to try and do it, my family and friends that know about it, they are like the first to tell me like, oh, don’t do more than you can handle, and it’s like it kind of makes me feel limited, you know, yes. I don’t like it. I don’t like it, it’s a dreaded disease, it is a disease I know it’s implications and it’s something that sometimes I just like live in denial and not even think about it because I know the complications, I know the implications, I know how it affects all the organs of the body and what it can do, so I just don’t like sickle cell anemia, that’s it in a nutshell.

Sarah White has felt very limited all her life, she would have loved to reach her full potential, but she fears she has not. She feels that quality of life she desires, she believes, is out of reach for her:

Um, it has impacted it a lot in regards to my health, the quality of my life. Yes, just like I said earlier that there are many activities, um that I want to that I can’t do, I’m limited, I’m limited because of the sickle cell disease, and I just feel that the quality of my life, SCA has affected it. I haven’t reached the potential in which I would have loved to reach because of this SCA really. So, yeah it affected the places I want to go to, things I want to do, activities are limited too. Yeah, it affected it. I can’t say it hasn’t, I have to put that into consideration first before anything, so I’m not like the normal person you know, I’m different you know, I can’t do things the same way other people do things, I can’t, yes.
Similarly Beth Brown noted that SCA has affected many aspects of her life including not taking anything for granted. She expressed that she has to be extra careful in regards to her assets and liabilities; therefore, she has to carefully plan her future. She stated:

Well, it makes me more, it just cost me to not to take things for granted and to make sure that everything is planned, you know. It has helped me to plan more, to plan more carefully, to set things aside. And it has helped me to be more diligent in regards to finances and things such as that. Because we cannot take things for granted, with sickle cell, we shouldn’t take things for granted, we are born with this, we are living with this all of our lives, we don’t know what’s going to happen with us.

Beth Brown’s future plans have been extremely limited because SCA has affected her organs, especially her lungs. She divulged, “tremendously, in every aspect it has affected the quality of my life. What I have done or where have been, you know sickle cell affects it, but it affects your organs, it does all kinds of stuff to you. It has affected many aspects of my life.”

Anita Green would have liked to continue her education, but she realized that the stress of schooling many times brings on a crisis; therefore she felt she could not really make any future education or career plans:

Having SCA, being a person that gets sick so often and especially when stressed, stress really brings on crisis a lot so I just really couldn’t have any future plans or plan for the future. I can make plans to continue my education but even with that the thought is there and then I start to put things in action to manifest that thought, but still knowing that at any given time I would go into a crisis so I couldn’t really make any set of future plans.
Like many people with SCA, Anita Green developed other health complications which have extremely limited her future plans and quality of life. Anita explained:

Well at this age now where things are much much difficult for me, I’ve developed other complications, I really don’t have any future plans, my life is at this point, it is one day at a time. And been able to manage my breathing, manage my pain, and take my medication. So for me, at this point, I don’t have any, any future plans.

Jeff Gray realizes what his limitations are, what extremes he can do physically and how to deal with the management of SCA pain which requires him to be as inactive as much as he can be. He expressed that he has a full life; he refrains from drinking, smoking, he is a vegetarian and he is very conscious and cautious of his diet. He enthusiastically explained:

I know what my limitations are and take them as another part of life, that I have to deal with and knowing the limitations, knowing what extremes I can go to physically and what issues I have to deal with whether it be from a dietary stand point and management of life, those things I am aware of, my sense of self is an awareness of who I am and what limitations I have based on the qualities that I can.

Jeff Gray continues to manage his life, it does not dominate his thinking, he says he lives the best way he can in the eyes of God. He says, “I do not constantly think I will die tomorrow or the other day, those are not thoughts that cross his mind.” Even though SCA impacts Jeff Gary’s quality of life, he deals with it: “SCA impact quality of life, my quality of life is hinged upon my sickle cell, as the disease would manifest itself with crisis or something of sort I guess ….. I try to manage it, but the truth is that I think am careful a lot, I try to be careful in what I do, what schedule I can keep, and so on that’s probably how I manage it.”
Jeff Gray stated that some people with SCA have been marginalized in the healthcare section because the healthcare professionals have been taught that all people looking for pain medications are not actually in pain, but looking for drugs to support their habit. Jeff Gray said that there should be more sensitivity built in the healthcare communities and not to treat all individuals as drug seekers. Even after having gone to the same hospital emergency room numerous times for SCA pain crisis, usually the person does not see the same healthcare professional. Therefore, SCA patients have to explain to the healthcare professional again and again and again that they are in excruciating pain and need pain medication. Jeff Gray stated:

The first thing I’m going to say is that it may be some people of that population who might be marginalized. I think in the healthcare section they might think some people are coming in for drugs so to speak. There is need for more educational sensitivity to be build in that community with individuals who offer healthcare who by definition by virtue of their profession who offer help to sickle cell, particularly in the sickle cell community. So I would say education and sanitizing people to the reality of the disease. And the other thing could be done would, that I think would be done in addition to that would be from the people with sickle cell to have a community where they themselves are working to building their own awareness of how to negotiate with the wider community and again it would begin with the healthcare professionals and then the wider community of other professionals on how to deal with the disease, so that would be something in practical terms, to know how to speak intelligently, to help them understand, those would be some of the practical things.
The findings seem to indicate a strong link between educational, social, future endeavors and quality of life of the study participants. The presentation of the findings is supported by a table for each emerging theme and several of the narratives that emanated from the findings (see Appendix K for tables 4.3 to 4.15). The aim was to showcase participants own words, and to provide a credible account of the nature and quality of their experiences. Because of the interconnectedness of the complex nature of SCA, the findings are closely related to one another. Therefore, the findings may overlap and intersect across themes and may support multiple themes. Thus, some quotations may appear more than once, but with a different purpose and meaning. Presented below are the documents reviewed and the researcher’s note on reflective memos.

**Document Review**

Data from the interviews was supplemented by gathering various artifacts provided to the researcher by the participants. Two participants provided documents, one participant provided a biblical passage, and the other participant provided two articles and a photograph. The other two participants did not provide any documents, but they provided insight into what gives them fortitude and resilience to live with SCA. Valuable and new information was obtained from these documents and from the participant’s personal insights. These documents validated and affirmed that the researcher has obtained supplemental documentation for this research. The following sections explain the documents each participant chose to share.

**Anita Green.** Anita Green presented three documents, two articles and a photograph: (1) *Airline Travel in Sickle-Cell Disease?*, (2) *Travel Recommendations for Patients with Pulmonary Arterial Hypertension*, and (3) A photograph of Anita Green when she was pregnant with her
son. Anita Green developed Pulmonary Arterial Hypertension (PAH), a serious health complication caused from SCA. Anita Green experienced some difficulties obtaining reimbursement from an insurance company for supplemental oxygen she received on an airplane flight five years ago. She stated that she believes nobody cares about SCA. Anita Green expressed that when she was diagnosed with PAH a few years after, she is now able to receive her reimbursements from the insurance company with fewer problems because of the PAH not as in the past with SCA. Anita Green felt that SCA was not deemed as important as PAH which Caucasians can acquire, as well as black people. Now, after being diagnosed with PAH, she does not experience any problems obtaining supplemental oxygen which greatly helps with her SCA as well. Anita Green stated:

Too very difficult questions for this particular disease and the reason I would tell you this is because nobody in this country really cares about a disease that only affects minority, that mostly, doesn’t only, but it mostly affects minorities. It doesn’t only affect blacks, but it mostly affects blacks, you know the Italians they have Sickle Thalassemia and you know there are other groups that have certain forms of the disease, but sickle cell anemia is mostly affecting the black population and nobody really cares about that. So I’ve had experience with my insurance company trying to get money back when I travel and pay for my oxygen and even now when I send in my notice for reimbursement and I have to say I have Pulmonary Arterial Hypertension and that’s why I need oxygen, I would have gotten my money back with no problem. But the battle I had to battle with them because of sickle cell, nobody cares about sickle cell you know I am just being very, you know very honest.
Anita Green now realizes she needs several things in order to secure oxygen on a flight, a doctor’s prescription, airline notice in advance and permission from her insurance provider that they will pay for the oxygen. Now that she secures these three necessities, she no longer has any problems obtaining a reimbursement on an airline flight. She still secures her reimbursement under PAH rather than SCA. Anita Green stated:

We are marginalized, we are stigmatized, we are ostracized. You know so um, I don’t know there is anything the school system you know that the school system can do and you know that may be regional, that maybe you know, if you have an area of black students where there is more black students and you have more students with the disease, I don’t know what the school system would compared to their blacks who live scantily maybe in suburbs and what not and you go to all white school, it would be very difficult for black students with SCA, living in a neighborhood where the school is all white, it’s not going to be easy.

Anita stated that if a black student living with SCA goes to a predominantly white school, she believes that a short educational discussion with their peers about the disease would be very beneficial and helpful to the student with SCA.

When asked to talk about the photograph based on past or present moment experiences with SCA, Anita Green shared:

That is a picture of me when I was pregnant. You see that is a maternity top. I didn’t, I wasn’t that big, I carried nine months, but not big. From the back when you saw me walking, from the back you wouldn’t even know I was pregnant. You couldn’t tell that is, I was pregnant there. So I guess I chose that picture because I remember growing up, they
said I couldn’t have children, so the lack of education about sickle cell and the fact that
they would prefer you not have children to pass the disease unto to children, that was not
available, but they just said you could not have children. So when I got married, I got
pregnant right after, and as a matter of fact, the only nine months in my life where I
actually didn’t have any pain crisis. Maybe one month before nine months they did
induced labor, they wanted to induce labor and take him actually because they didn’t
want me to go into a crisis, but let say you know one of the only eight months in my life
that I never was in a crisis was when I was pregnant. None whatsoever. None whatsoever
that eight months, none whatsoever. But I think that is why I chose the picture. The
picture reminds me of a period of time where there was no painful crisis.

Anita Green stated that the photograph also influenced or helped shape her educational
experiences as a person living with SCA:

Well based on the picture is the fact that I even got pregnant in the first place was
surprising to me because when they said oh you can’t get pregnant, you can’t get
pregnant. I just thought I couldn’t get pregnant period. And when it was time for
contraceptives, they didn’t want to give any oral contraceptive because of the disease, I
ended up with a diaphragm using the diaphragm as a form of contraceptive, but I just
really thought I couldn’t get pregnant. I didn’t know, it is not that I can’t get pregnant, but
they would have preferred, they didn’t explain, there was no education to explain about
you know, ok getting pregnant for somebody who did not have a trait or did not have the
disease and what that would mean to your offspring, all that came long after. So just
being, just getting pregnant was wow; you know I could get pregnant, yeah.
This photograph represents a period in Anita Green’s life when she was pain-free for 8 months of her pregnancy with absolutely no SCA crisis. It was a monumental time in her life; she was pain-free and also happily carrying her first child that she believed she could never conceive. She realized at this time that she also had much more to live for; this was a great incentive to Anita to return to school and complete her bachelor’s degree. Anita believed she needed to obtain a higher education in order to sufficiently supply the wants and needs of her child in the manner she believed he should be cared for. Each time she would falter in her life, she would gaze at this photograph and would realize joyfully what she must do to continue her journey to a higher education.

**Jeff Gray.** When Jeff Gray was asked the question, can you talk about the document that you brought in today based on your past or present moment experiences with SCA? Although, Jeff Gray did not provide the researcher with any documents, he did reflect upon many aspects of his personal life:

I know that I can reflect on my life you know, I can look at the folks around me that I shelter. By becoming more educated, I look at spiritual props about me, religious literatures and so on and I think that those are sources of inspiration. For me, I look at photographs of my family and I think they also add meaning to my life in the sense of my feelings of connectedness to them, and their capacity to keep me motivated and have me stable. Those are things I think about, those are the things, yeah.

When asked about what influenced or helped shape his educational experiences as a person living with SCA? Jeff Gray stated:
I think it is the idea that or the fact that no one in my immediate family ever suggested that I couldn’t become what I wanted to be even as a person with sickle cell. I think it was the fact that the people around me, my immediate family never suggested, they never suggested that sickle cell was a limiting factor; and they always thought I could become anything I wanted to become. By the grace of God I think that was what motivated me.

It is Jeff Gray’s believe as he looks around and sees his family, he realizes that his father’s influence on him to obtain a higher education was beneficial, he realized that he was correctly motivated by a man who himself had very limited education. It was as though his father had gifted him with immeasurable wisdom and foresight, to this day has allowed Jeff to become the man he is with a strong belief in a higher being and a need to help mankind to the best of his abilities. In spite of Jeff Gray’s battle with SCA, he maintained a full schedule in high school, also in college up to and including receiving a PhD.

**Sarah White.** When Sarah White was asked to talk about an artifact based on her past or present moment experiences with SCA? Sarah White shared her favorite bible verse from *The Book of Philippians.*

The one thing I would like to talk about is a scripture from the bible because am a Christian and the Christian foundation is what have really based my life, my all support on and that’s what’s been carrying me through. There is this particular verse of scripture in the bible from the book of Philippians chapter 4 verse 13, and it says: I can do all things through Christ which strengthens me. Which means there’s nothing any other person in this world can do, any other person not living with this disease, any normal healthy person can do that I cannot do, I can do everything I choose or want to through
Christ, just by putting my trust in Christ who strengthens me, which means physically, emotionally and all that, it strengthens me to achieve, achieve whatever I want to do in life, so that’s what I base my life upon, and it’s been carrying me on and I know I can actually do all things really, everything, everything I want to become I can become through Christ. So that’s it really the key thing that has seen me through, seen me through my education, my family life, my ability to not just have one child, but to have two children, have a good family life, you know, to still have a husband and those are all the support, yeah. I see myself as normal really, right now, I see myself as normal and happy, yes because of the word of God.

Sarah white was asked to explain how the bible verse from *The Book of Philippians* influenced or helped shape her educational experiences as a person living with SCA? Sarah White stated that:

Yes, because when I see my colleagues, when I see them like studying, um you know reading and studying through courses that is like almost to me is like oh with this disease, how would you even be able to cope? And you know after studying will you be able to even work? Have a meaningful life or job with your disease, with this? But with this scripture, it lets me see myself as like even better than them really, that they can achieve it, I can achieve it too. So that scripture makes me see that that I can do all things and helps me, yes. So with my education it has helped me. Belief in myself that I can do it, I can do it and have done it, you know, have done it and I know the sky is my limit and I can even do some more once I just put my heart to it and all that, I can do all things through Christ who strengthens me. I think basically that’s it. I’m just a happy person and
I know that sickle cell anemia will not beat me, so rather than that, I will beat this disease and I’m just trusting the Lord for much more breakthrough in medical science so there would be a complete eradication of this horrible disease.

Sarah White’s need to obtain a higher education has been helped tremendously by her belief in Christ and the bible. When she felt discouraged, she would read a few passages in the bible, especially a scripture from *The Book of Philippians* chapter 4 verse 13 that says: “I can do all things through Christ which strengthens me.” Sarah makes several references to her Christian foundation, the bible, Christ and the trust she has in the Lord as sources of motivation to explain the belief she has in herself, she says, “I can do everything I choose or want to through Christ, just by putting my trust in Christ who strengthens me.” Sarah’s faith and belief has seen her through her educational accomplishments of obtaining a bachelor’s degree, her family life, her ability to have more than one child and to have a husband that is very supportive. It also reflects her will and desire to accomplish her goals in life, she says, “I know the sky is my limit and I can even do some more once I just put my heart to it and all that, I can do all things through Christ who strengthens me yeah.” For Sarah, her Christian foundation and faith is what has supported and carried her through the ebbs and flows of her life.

**Beth Brown.** Based on past or present moment experiences with SCA, Beth Brown talked about a newspaper interview she was invited to do. Beth Brown was asked to speak from personal experience in regard to SCA. Beth Brown shared her top takeaways from the interview:

Well, um the newspaper they were doing awareness, they were doing sickle cell awareness [for my local] newspaper. They contacted me at the office that I worked for and they did an interview. They wanted to put a face to the name of sickle cell, they
wanted everyone to see the face and …… they wanted to see what a person goes through with sickle cell. You know, everything could be fine in one day, and then the next day you could be in the hospital fighting for your life. So [the newspaper] was able to capture that, [they were] able to take photographs, and with the article [they] wrote out, so that’s basically what [they] wanted to capture, what [they] captured.

When Beth Brown was asked about how the newspaper interview influenced or helped shape her educational experiences as a person living with SCA, Beth Brown responded:

Well, what helped me really to want to become a nurse and to educate myself and to get educated and all that, what did that was the treatment I received in the hospital, that’s what did it. That’s what did it, that’s what did it. It made me say, when I was about ten years old I was like am going to be a nurse, and I’m going to change some things, I remember saying that because the way I was constantly being treated, you know the way we are looked at, you know like we are drug seekers, we are beneath everyone, all of that, and I’m sad to say this happens until this day, you know so I’m just one of those people that always wanted to make a change, that’s all. To simply change some, to simply change some of the ways I was being treated like I wasn’t going to amount to anything, like I was nothing, that’s what did it.

When Beth Brown was a child of approximately ten years of age, she decided she would become a nurse because of the way she was constantly being treated, and as she grew older, she also realized that she was being looked down upon as many people treat SCA patients as drug seekers. This treatment was a motivating force that persuaded her to seek a higher education and to become a nurse. She decided she wanted to possibly educate and transform the way people
regard SCA persons. Beth Brown fulfilled her childhood dream of becoming a nurse, her expertise in the field has allowed her to be interviewed by a newspaper journalist who was assigned to secure and feature a story of an SCA patient in the newspaper. Beth Brown’s story of being a nurse living with SCA, who also specializes in the treatments of patients with SCA, as well as a mentor of SCA patients firmly fixed the attention of the journalist. Now that Beth Brown has manifested her childhood dreams, she is concentrating on making people more aware of the plights of people living with this disease. Beth Brown continues to mentor young individuals living with SCA explaining that a higher education is essential in order to expedite their standings in their chosen professions and secure their future.

**Reflective Memos**

Data collected from the interviews was also supplemented by reflective memos created by the researcher. As detailed by Lincoln and Guba (1985), reflective memos are an important and helpful tool for generating ideas generated during the analysis. Thus, memos were used throughout the collection process and during transcription to write the researcher’s thoughts about the data and to form ideas. These notes helped the researcher to record insights gained and to develop emerging patterns and themes found in the data. The memos aided the researcher’s thoughts, perceptions and reflections during the interviews which enriched the data, while adding credibility and trustworthiness to the information gathered from the participants.

As the researcher reminisces about the four incredible research participants, it was realized that all four individuals have many things in common. For example: all four of them are black, they were educated in the same decade, three of them went to all black schools in the land of their birth which are black countries, one participant went to a predominantly black school in
America. All four individuals received higher than average marks in school. All four individuals expressed they had very good teachers in their primary and secondary schools, as well as outstanding professors in their colleges/universities. They are stupendous individuals themselves, one having obtained an associate’s degree, two having obtained bachelor’s degree and one having obtained a Doctor of Philosophy (PhD). They are all outstanding citizens of their communities.

Chapter Summary

This research sought to explore and describe the educational experiences of individuals living with SCA. The four prominent findings were divided into themes: (1) SCA Pitfalls to Higher Education; (2) SCA and Individual Resiliency; (3) The Challenges of SCA; and (4) Living with Uncertainties (SCA). Through the process of interviewing the participants, completing the data collection, analysis and writing, the researcher was able to carefully identify key patterns, ideas and themes that captured each participant’s shared experiences. While conducting the interviews and during the analysis process, it was noticeable that there were common threads among participants’ perceptions, ideas and experiences, but with unique insights in each of their narratives. Several themes emerged which helped to illuminate the core of the research question and its goals. People living with SCA are faced with multiple challenges every single day; and the participants in this research are no stranger to its impacts and effects, but through their resilience and perseverance they are cautiously able to battle against SCA and to climb and conquer one step at a time.

It takes courage and strength beyond measure and open vulnerability to share one’s story. Hence, it has been a true honor, a sincere and honest appreciation with immense privilege to
have been allowed by each of the participants to conduct two interviews with each one of them for the purpose of this research. I would like to thank all four participants for allowing me to have a personal view into their lives. Chapter 5 interprets the findings of this research, draws conclusions, considers implications for theory and research, and presents recommendations for future research. In addition, the researcher discusses her personal thoughts – SCA and Great Expectations: A Reflection of My Research Journey.
Chapter 5: Discussion of Findings

The focus of this final chapter is to review the purpose of the research and methodology. To discuss the findings, interpret and describe the significance in relation to the overall study, discuss findings in relation to theoretical framework and the literature reviewed, and draw conclusions based on the findings of the research. Following the conclusion, implications for theory, implications and recommendations for future research will be highlighted.

Revisiting the Problem of Practice

The purpose of this qualitative research sought to explore and describe the educational experiences of individuals living with SCA. This research is different from the general (current and previous) research on SCA which have primarily focused on clinical and medical aspects such as blood transfusions, experimental treatments, pain-relieving medications, complications and so forth. This research highlights some of the problems and issues missing from academic journals and scholarly literature concerning SCA. Thus far, relatively little research has been done that focused specifically on the educational experiences of individuals living with SCA, largely because the attention has been greatly focused on some of the aforementioned areas and aspects of SCA which are critically important. Nevertheless, a retrospective look at the educational experiences of individuals with SCA is equally valuable and; therefore, essentially of great importance to the extensive and growing body of literature on this topic. Individuals with SCA need a voice to have their own opinions expressed and feelings heard; which this research strived to do through participants’ narratives.

The purpose of this research sought to focus on the educational experiences of individuals living with SCA who have reached the age of 25 years or older and have earned an
associate’s, a bachelor’s, a master’s and/or a doctorate degree. Several themes informed and framed this research effort. These themes were divided into four areas: (1) SCA Pitfalls to Higher Education; (2) Resiliency: Living Through SCA; (3) The Challenges of SCA; and (4) Living with Uncertainties (SCA). These themes provided insight into the realities and lives of each participant. Each participant reflected deeply on elements of their unique educational journey as person’s living with SCA. Each participant’s own unique struggle played a role in their educational goals. Participants’ perceptions, inner strengths and resilience that helped them to achieve in spite of setbacks, were also viewed through the theoretical frameworks of Social Disabilities Theory (SDT) and Individual Resilience Theory (IRT). It is hoped that this research will be a useful resource to raise more awareness and ideas, and would become a useful body of knowledge on the topic of SCA.

**Review of Methodology**

The methodology utilized to gather and analyze the data for this research was carried out through a narrative approach. A narrative approach was well suited to the context of the research because it allowed participants to tell their own stories in a chronological sequence of events. Data was collected through in-depth individual open-ended interviews. The interview processes were supplemented with documentary evidence provided by the participants, and the researcher’s reflective memos during the interview and throughout the transcription process. To secure and maintain trustworthiness of the research findings, three validation strategies were employed: (1) threats to internal validity, (2) transferability, and (3) confirmability.

**Discussion of Findings, Interpretations and Significance**

Through a careful and structured step-by-step analysis of interview transcripts, there were a number of themes that emerged through the participants’ stories. These insights (themes)
offered lucid and thoughtful interpretations for the discussion below. Collectively these themes were then coherently developed and anchored into substantive themes. The following themes and are presented in Table 5.1.

Table 5.1: Themes

- SCA Pitfalls to Higher Education
- Resiliency: Living Through SCA
- The Challenges of SCA
- Living with Uncertainties (SCA)

These overarching themes are discussed in more detail below.

**SCA Pitfalls to Higher Education.** The impact of SCA can marginalize the education of individuals who suffer from this disease; it can prevent the ability to pursue and obtain a college degree. The findings from this research reveal that there are many barriers that have been identified through each participant’s own account and stories. Although these specific individuals have scaled those barriers, unfortunately there are countless others living with SCA that have been unable to obtain such goals. For each participant in this research, not only did they fulfill their personal purpose and goals, they were also able to conquer some of the obstacles that deter most people with SCA from pursuing an education of their choice. Participants reported that the influence of family ideals played an instrumental role on their desire for higher educational levels and a yearning for increased knowledge and educational attainment.
Education is a fundamental necessity in today’s economy, but for many of those with SCA, the journey to higher education is full of pitfalls. It is a balancing act to achieve scholastic success while coping with SCA and its many complications. College education is a prerequisite and a ticket to an established career and beyond. Therefore, each study participant recognized the significance of higher education as inevitability for individuals living with SCA, as it opens up many different avenues for career and job opportunities, which may also decrease the frequency of SCA crises. The findings from this research highly suggest that higher learning today is the way to the future; the educated will dominate the jobs and career paths of tomorrow. Individuals living with SCA face many hardships and pitfalls in acquiring an education, these barriers tend to makes it extremely difficult to have opportunities in accessing higher education. Education higher than a high school diploma maybe essential for students living with SCA as it is quite advantageous to be able to obtain a white-collar employment versus a blue-collar job. Financial hardships can literally make the difference between life and death of a person living with SCA. If the family of the person with SCA are financial secure, it is much easier on the family and the SCA student to live a reduced stress life.

**Resiliency: Living Through SCA.** Resiliency supports the remarkable optimistic outlook and the inner resiliency that each of the participants have in spite of the severe challenges they face on a day to day basis. The information from this research indicates that resiliency plays a significant role in each participant’s coping mechanisms and their ability to recover swiftly from a sickle cell pain crisis. Coping with a disease such as SCA is overwhelming, it comes with a lot of stressful and/or traumatic experiences that can make everyday life dismal and miserable. The findings of this research also suggest that resilience
makes coping with SCA more endurable and tolerable while trying to obtain a higher education. The finding further indicates that there is a strong correlation between stress and SCA crisis as stress plays a major role in the onset of painful crisis. This has been identified from the narratives; participants stated that they try to minimize or avoid stress as much as possible.

This research provides data that raises the importance of the relationship between persons with SCA and their families. Based on the findings, family influences are key indicators that help foster coping strengths when dealing with a life threatening illness such as SCA. Each participant has revealed that family support is upmost to them in times of a sickle cell crisis. Each participant revealed that family support is upmost to them in times of a sickle cell crisis. The findings strongly suggest that family resilience, hardiness and positive health care support are associated with the ability of each participant to bounce back from a sickle cell crisis.

An overly protective and cautious parent tends to train the person from childhood to adulthood to help build resilience to SCA. Family structure can often create emotional support and encouragement that is needed for a psychologically sound independence and/or interdependence. Family function is an essential part of SCA management and it fosters smooth and swift recuperation from pain crisis. Each participant offered insight into how SCA affects them, their family members, and how they have managed together, the healing and recovery process within each of their respective family through resiliency. Overall, the stories from each participant demonstrate how their families have managed the hardships and tribulations that necessitate caring for a member/s of the family that have SCA.

It was discovered through the research that seventy-five percent of the participants found much of their strength to cope with SCA through religion and spirituality. The bible seems to be
a very prominent theme in their life, a few of the participants believed that God would help them through their crises. For them, they believe that quoting scriptures from the bible as well as reading the bible gives them the strength and fortitude to help cope with the pain associated with SCA. Participants receive inspiration from their belief in a higher being in order to help them cope with SCA difficulties and setbacks. For some of the participants, the influence of religion is essential for success in order to cope with the stress caused by SCA.

**The Challenges of SCA.** Individuals living with SCA encounter a wide variety of stressful events or situations that normal people without SCA can never relate to. Some of these conditions are beyond their power to change or prevent such as, getting caught in a rain storm, getting into an overheated car in the middle of summer time and finding the air condition does not work, waiting at a bus stop or train station in the middle of winter time and having the bus or train being delayed before you get home - you are in a crisis. Many times while studying for an examination, the following day, a crisis will occur because of the stress and anxiety caused by the upcoming test or while in the examination room itself, the person would have to leave before a crisis is coming on or has evolved in a full-blown crisis. Some things that will trigger a crisis, a person with SCA will try to avoid, but other stressful situations are unavoidable. Many times during an educational endeavor, stressful situation arise causing truancy in the person’s education. This truancy also causes a stressful situation by itself as the person is becoming deficient in their learning and school-work.

Some people deal with stress in other ways such as, being attentive to their health, cognizant of their limitations, and always being aware of their surroundings and trying to eliminate as much as possible the emotional impact SCA has on oneself and the family. The
findings of this research suggest that SCA has a detrimental effect on the quality of life of the person, and also places a great deal of stress and strain on the family. When a SCA family member suffers a crisis, it affects the entire family whether the member is a child or an adult. As a child, the parents and siblings, in most families assist the stricken one as much as possible – caring for the individual, getting medications, food, water and et cetera. If necessarily, taking him or her to the hospital for treatment. Many times, one of the parents must stay in the hospital or at home with the child to see that their child’s needs are being met, while other family members and friends visit daily to cheer the person up. As an adult, the person is called daily to see if they are normal or in crisis, if in crisis and in the hospital, it puts the whole family on high alert with telephone calls daily to the hospital checking on the person’s condition. Many times parents are affected by a sick or disabled child as it causes a one income or limited income family. If it is a single income family and that parent has to devote time to their sick child, it causes tremendous hardship on the family unit. When the child strives for a higher level of education there is little or no money to assist the child with the cost. This places another financial burden on the family. This may also cause the child to resort to a blue-collar job, which causes more SCA crises due to the physical strain of the job, which also can lead to permanent disability and probably an earlier death. The family also is greatly affected as SCA is an inherited disease that can drastically affect the children, although they may not have the disease or only be carriers. The future generations will also be greatly affected. This is a burden that is shared from generation to generations. This disease has the effect of sabotaging the person’s educational ability and goals, as well as their future endeavors.
Living with Uncertainties (SCA). The life of a person with SCA can mean living one’s life in the unknown with a future that is uncertain. For each participant in this research, SCA is an impediment, a barrier that must be gently pushed aside, yet embraced and nurtured in order to prevent or avoid the next pain crisis or episode which can cause a lapse in educational endeavors. For many individuals with SCA, school can be a tremendous challenge not knowing if the education can be completed, then not knowing if a job will be obtainable and maintainable and then, always living with the uncertainties that a crisis is always on the horizon. The struggles, the uncertainties, the fears, the pain and suffering can impair the functioning and/or progress of one’s efforts and educational achievements.

The findings of this research revealed that some people with SCA are plagued by chronic loneliness, life-time (long-term) solitude and seclusion caused by this chronic condition. SCA is a condition that can often induce solitude that can last a life-time; each SCA patient knows his or her limitations which causes solitude. For instance, one cannot get stressed, too cold and too hot, too tired, too exhausted, and cannot show too much emotions or sadness because all these things plus many more can cause a crisis. For instance, the social life of a person with SCA can be marred by the limitations that are imposed on them by the disease causing their peers to reject them overtime. Peer pressure may cause SCA students to do strenuous activities which may cause a crisis. If a crisis occurs too many times, the SCA student would tend to isolate themselves from their friends in order to avoid a crisis therefore, possibly losing friendships. These are some of the factors that cause solitude.

Three of the four participants stated that SCA has tremendously influenced the quality of their lives. Each of them expressed the desire to obtain more education, but all have not done so
because of the limitations placed on them from SCA. They realized it was nearly impossible because of the length of time it took to achieve the level of education they have now (bachelor’s degree) due to the reoccurring pain episodes and the necessary hospitalizations. Any career choice or decision and future plans in their life always require the need to consider SCA first, whether those choices would put more stress on their body. Therefore, a decision to go for their career choice or not must be based on their ability to withstand the stress. SCA can prevent a person from achieving what they may want to achieve, such as the desire to be a geologist, but realizing that you cannot because of the necessary walking and climbing in a geologist field. SCA is an ever-changing kaleidoscope of life’s complex set of circumstances and events.

**Discussion of Findings in Relation to Theoretical Framework**

This research was informed through the perspective of Social Disabilities Theory, SDT (Oliver & Barnes, 1988) and Individual Resilience Theory, IRT (Masten & Osofsky, 2010). SDT and IRT supported and informed the research’s conceptual framework. Each theory together as well as separately served as lenses through which each participant’s story was narrated. These two theories have allowed the researcher to burrow deeper into the important themes that arose during the interviews.

**Discussion of Findings in Relation to Social Disabilities Theory (SDT).** SDT is divided into three categories called barriers – cultural, environmental and economic. Cultural barrier proposes that because society has negatively shared attitudes towards people with disabilities (Oliver & Barnes, 1998); and does not expect people with disabilities to perform up to the same standard as the rest of society with no disabilities. This mind-set more often than not consigns people with disabilities to lower job standards – low-skill, hourly wage and blue-collar
jobs which tend to alienate them and their aspirations for higher job standards – highly-skilled and white-collar jobs. The findings from this research has suggested that an understanding of some of the environmental and support structures that have positively influenced all four participants may be a useful tool that could influence and guide other individuals with SCA to pursue higher levels of education as well.

This research exemplifies some of the concepts central to SDT which advocate that people who have disabilities encounter a wide range of hurdles; examples include physical, cultural, environmental, economical and systematic barriers. Oliver and Barnes (1998), suggest that barriers often lead to the exclusion of people with disabilities from almost every aspect of everyday life. SDT implies that environmental barriers can and do impact people with disabilities to disproportionate accommodations that are afforded to people without disability. Therefore, modern surroundings are inclined not to benefit people with disabilities (Oliver & Barnes, 1998).

This research also highlights close association between SCD/SCA and SDT. The general lack of interest, awareness and education about the topic of SCA may have caused the society to resort to preconceived notions and judgments, ill-informed and uninformed opinions, stigma, bias, unfair treatment, ignorance, intolerance and inequity of people with SCA. These misconceptions and criticisms have caused an environment of silent companions for some people living with this disease. These downbeat causes are interwoven with SDT, which suggests “individuals with impairments are not disabled by their impairments, but by the way society is organized,” (Oliver & Barnes, 1998, p. 1); and by the way societies behaves and act toward them. In spite of the misconceptions that society has towards people with SCA, each participant in this research is able to manage the illness well enough to lead fairly normal lives.
Discussion of Findings in Relation to Individual Resilience Theory (IRT). The themes that emerged across this research are consistent with IRT that necessitates an individual success. Findings from this research support the essence of IRT which affirms that resiliency can enable a person to find strength to rise above or to endure difficult experiences (Masten & Osofsky, 2010). SCA and IRT have similar parallels. Individuals with SCA are constantly adjusting daily lives to complications, challenges and struggles that SCA may produce. Therefore, they always have to maintain a resilient attitude in order to prepare for the daily challenges and stressors SCA will bring. Masten and Osofsky (2010) conceptualized IRT as a positive adaptation despite adversity, because resilience is tied to strengths of individual, family and friends. The use of IRT based lens for this research has helped to establish that there is a direct link between SCA-related stress, coping and resilience.

Masten and Osofsky (2010) embraced the notion that resilience is an innate or learned characteristic that some people possess to enable themselves to cope when in the midst of a crisis, “it is an ordinary rather than extraordinary processes” (Masten, 2001, p. 227) or development. Thus, the conclusion is that most individuals who are considered resilient have been through “significant threat to their development” (Masten, 2001, p. 228), past or current hazards that have potential disrupted their normative development (Masten, Best & Garmezy, 1990; Masten, 2001). Each participant in this research have used their ability to rise above their difficulties by utilizing the resilience capacity and drive each of them have learned and retained despite many SCA challenges. Many hardships have been encountered on their way to a higher education, and most of them have been triumphed over by resiliency and fortitude.
Another characteristic of IRT evident in the findings is that endurance is rooted in the belief that individuals can learn to cope and adjust or adapt to life’s challenges. These principles are important to individuals living with SCA as it is based on healing and overcoming adversities. Not only does IRT characterize elements that are beneficial for individuals with SCA, it also clarifies to an extent the everyday life experiences of all of the participants. IRT bolsters innate strengths, skills and abilities; it supports the growth of the resilience of the individuals to overcome difficult and challenging experiences (Masten, Best, & Garmezy, 1990). With this premise in mind, it should be noted that each challenging experience have enabled each participant in this research to continue to defy the odds, cope with the stress and the experiences associated with SCA. IRT was evident throughout the findings of this research. This theory was appropriate for conceptualizing the educational experiences of these participants, each one of them have been able to thrive academically in spite of difficult circumstances with optimism, hope, determination and perseverance.

**Discussion of the Findings in Relation to the Literature Review**

The findings of this research align and are connected with current literature presented in chapter 2. The literature review focused on four aspects of SCA/SCD: Medical, Psychological, Sociological and Educational. The literature review began with a conceptual and theoretical description of the research’s framework. It also showed the emotional and stressful situation placed upon family members of persons living with SCA.

This research confirms what the literature suggests about SCA/SCD, that it is a physically stressful condition that comes with constant sharp pain which affects how a person with SCA lives their daily life. People with SCA are often in acute pain crises. These crises (also known as episodes of pain) require strong analgesics which in most cases require hospital administered
analgesics (a type of medication that alleviates pain), intravenous fluids (hydration), and blood transfusions if to be found necessary. Participants in this research all were affected in their education by SCA pain crisis, but with medical interventions, they were able to continue with their learning and acquire higher levels of education. Although one of the individuals could not acquire her degree until she was in her mid-forties because of many pain crises. This is a perfect example of resilience, the ability to cope and the medical knowledge that enabled her to do so. These pain crises have the tendency to manifest so often that it requires a regimented lifestyle and significant modifications to one’s life, in order to limit the amount of undue stress and crises. A regimented lifestyle is one of the furthermost achievements in the life of a SCA patient in order to acquire and improve the overall quality of life and well-being of the patient. It is a fundamental facet of coping with the illness.

Several of the literature reviewed in chapter 2 shows a considerable overlap with the findings of this research. One of the overlaps reveals that SCA students are reluctant to disclose their illness to their friends and peers for fear of ridicule. One of the participants’ was greatly affected in her elementary and high school as well as college years for fear of shame, ridicule and feelings of embarrassment. Another overlapping fact is that participants seemed to have fewer friends. They were basically loners and social life was very difficult because of the demands of academics, health and well-being. Another correlation between the study and the literature that was reviewed confirms that students with SCA have restrictions on their physical activities more often than their peers resulting in being ostracized, isolated and rejected. All of the study participants emphasized that unlike their counterparts, they were unable to run, swim, hike, play sports, etc., and these limitations were very frustrating for them.
Many of the literature reviewed discussed challenges faced by persons with SCA and the various ways these challenges maybe be surmounted, for example clinical, medical, sociological and psychological (psychosocial) aspects of the disease. None of the existing research examined the educational aspects of SCA through the eyes of the SCA participants themselves, to understand what could be done in the education arena and education community which would be beneficial and advantageous for SCA students in their educational quest. The findings of this research further revealed that persons living with SCA needs motivation and determination to overcome the hardships to battle the effects of SCA while attempting to obtain an education.

Conclusion

The research question that directed this research was: What are the educational experiences of individuals living with SCA? The participants in this research project have graciously shared their stories, insights and transformations as a result of their personal and educational knowledge as persons living with SCA. These four inspiring people have generously allowed the researcher to put their memories and experiences into a narrative form. Each account is full of hope, optimism, enthusiasm, perseverance and remarkable fortitude. Even during setbacks, their capacity to cope amidst adversities and life challenges, while still maintaining a compatible level of education is an experience only a person with SCA and their family will understand and appreciate the level of dedication necessary to accomplish their goals.

SCA is lifelong limitation on a person’s health; it is one of the most common inherited (genetic) health conditions in society, and one of the most misunderstood illnesses. Its effects are far more than the tiredness, listlessness and the lingering physical pain. It affects not only the person, but also family and friends. Many people with SCA also find that the illness seeps into
many different areas of their life such as, education, financial, social, emotional, religious and psychological. The effect of SCA can place a heavy burden on the person suffering from the disease and their families. Not having the ability because of financial situations to achieve their life dream of obtaining a higher level of education can have detrimental impact on financial status and resources. With support of caring family and friends, they can seek comfort and thus thrive in spite of the persistent and confounding challenges they are faced with on a daily basis. From this research, evidence suggests that caring families and good friends are important in dealing with the disease; as well as assisting in coping with the pain and stress.

**Implications for Theory**

This research explored and described the educational experiences of individual living with SCA. Findings from this research provide empirical research to support SDT and IRT, which may prove very useful with similar qualitative research, practices or methodologies using different styles in different contexts. The findings of this research corroborate and extend the fundamental concepts of SDT and IRT, and their underlying assumptions. The two theories confirm the correlation between the significance and the outcomes of the research. It also helped to gain new insights, deeper understandings that will provide noteworthy contributions to the research of SCA. The participants of this research have encountered many challenges as a result of their illness. The stories they elaborately and eloquently shared uncovered many hidden strengths, resilient traits and capacity to cope while completing their education or working. These findings will hopefully pave the way for improvements in the educational practice and awareness, and prospective studies of SCA.
Implications and Recommendations for Future Research

There is a need for future research to extend the scope of the findings of this project. This research could be replicated with a larger sample of participants to obtain higher diversity among persons with SCA. The research was limited in its scope to four participants as the right of privacy laws makes it extremely difficult to procure participants. Although, based on the research design and methodology that was chosen by the researcher (a narrative approach), a more detailed narration is appropriate from a smaller sampling of individuals because of the in depth and open-ended questioning that would be required to accomplish the task.

Future research may benefit from the information and stories obtained from these four individuals. For example, longitudinal designs could provide further evidence for whether pain and stress caused by SCA is greater in males or females. This potential difference between male and female could provide important information that may improve the drop out rate of students with SCA. There are numerous qualitative methods that may be useful and helpful in continuing to examine and describe the educational experiences of individuals living with SCA. An area to explore includes a larger qualitative research with recent high school graduates, who have decided not to further their education and to try to determine the reason why. Maybe, is it because of frequency of SCA pain crisis? Perhaps, financial burdens? A lack of desire, or is it another underlying factor? It must be stressed in the SCA community, as well as to the parents of students living with SCA that a higher education is essential to ensure that they may be able to obtain a white-collar employment that should be physically less stressful for their SCA health condition.
This research did not evaluate racial issues relating to the participants ability to have obtained a higher education nor did the participants mention having encountered any racial issues in their quest for a higher education. However, future research on SCA should look at the connection between race and racial stereotypes and how they relate to the educational development of students living with SCA. It has been determined that SCA patients when they are in pain crisis and enter the hospital are immediately stereotyped as possible drug seekers. A future research is needed to determine whether educating healthcare professionals of the need to treat SCA patients with dignity and to understand that SCA is a major illness and should be treated as such, and not immediately label them as drug seekers.

All four participants in this research informed the researcher of their supportive and positive learning environment. They emphasized that their teachers and professors had treated them fairly and respectfully. They did not assert any claims of racial profiling or racial issues concerning their scholastic experiences. Even though none of the four participants in this research expressed or mentioned any experience of racial issues or racial biases during their college/university years, there is a need for a future research to determine whether racial bias does exist with black students living with SCA in the United States in the primary, middle, secondary and higher education arena.

There are many reasons why a student may decide to drop out of school. For example, peer pressure and bullying can create an adverse learning condition for children with SCA. If racial conditions were evident to SCA patients, he or she might have cause to forgo and withdraw from their education. Therefore, racial profiling and other forms of racial experiences are detrimental in the learning years of individuals who suffer from SCA. It may affect their
well-being, it may cause them to become disengaged from school, and ultimately, affect their higher education attainment and also employment opportunities. A research on this topic may explain whether there are any reluctances, unwillingness or lack of enthusiasm of students living with SCA to pursue or continue with higher education because of racial bias and institutional racism.

Researchers on the topic of SCA in the future should conduct a one-one informational interview with high school students with SCA to try to determine what could be done to balance SCA and academics. This research may facilitate school systems in establishing additional modifications and accommodations that may enable students with SCA to maintain the same success level as their peers. This would benefit the students and assist them toward their goal of a higher education. An important value obtained from this research is that all the participants agreed that a mentor program is necessary for SCA students recovering from an extended pain crisis. A mentor or teacher assisted program may allow students to maintain their class standing and continue their education uninterruptedly. Future research should examine potential gender differences among individuals living with SCA. This is especially important because the male in this research project seemed to be doing quite well with his illness, his education and his profession compared to the females. This may determine whether males have a higher tolerance to pain when in a sickle cell pain crisis.

It is hoped that this research will be used as a credible and reliable source of information relevant to the knowledge and awareness of SCA. The findings from this research will hopefully serve as an invaluable source of information that will inspire and encourage many new empirical studies. It is also hoped that individuals living with SCA will find this research beneficial.
inspiring and informative. I would like to thank the four individuals who generously allowed access to their personal lives and stories, while giving up their time and energy to enable this research to be a buoyant and joyfully experience. I am filled of gratitude and appreciation.

**SCA and Great Expectations: A Reflection of My Research Journey**

“*Suffering has been stronger than all other teaching....I have been bent and broken, but – I hope – into a better shape*” Charles Dickens, Great Expectations. An important justification for this research stems from my personal interest as a patient of SCA. My reflection and personal experience with SCA has caused me to have a profound interest in the subject. Hence, my experience and understanding of the topic has expounded and has given me a new and unique perspective of the people (including myself) affected by this inherited disease. I was able to genuinely listen and learn from each of the participants, each reflection enabled me to see beyond my own thoughts. There seemed to be a level of comfort and easiness as we had a common bond and a shared camaraderie. We discussed experiences that have affected us in the past; we talked of our present happenings and our hopes for the future. I listened as they shared and reflected on their stories. I feel I now have a better understanding about the educational experiences of individuals living with SCA not having to only rely on my own experiences, but on the experiences and perceptions of others living with the same illness.

This research has challenged me to think differently, more boldly and courageously. It stoutly affirmed and confirmed my passion, my desire and my life’s purpose for research to promote a concerted effort that will accelerate global research, advocacy and pace towards a cure and eradication of SCA. We all have tried to manage SCA, but the truth is SCA manages us, for most people with SCA, they realize they have to make life-changing choices with somatic-
awareness, essence and purpose. Therefore, each decision they make in every aspect of their life is made with refinement and delicacy. All four participants also perceive each challenge not as a threat, but rather as a positive outlook that boosts their spirit and in turn, helps them to cope more easily with the daily affairs of life. Hope and optimism are important for those who live with this unpredictable condition. This research confirms that education is a pivotal milestone along the road leaning toward independence and beyond.

With SCA the future is uncertain, the unknown is worrisome, but the participants in this research have shown that through perseverance, determination and education, all things are possible. With great expectations, SCA is like a “suffering that is so deep, but not without hope” (Yang & Choi, 2001). This doctoral thesis has allowed me to travel a personal journey, exploring who I am, my strengths and weaknesses, and it has given me the coordinates for my future voyage.
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**APPENDIX A**

*Definition of Terms*

For the purposes of this research, the following terms have been modified and adapted from multiple websites. All sources are cited in footnotes. Each footnote corresponds to a numbered note directly in the text to indicate the publication information about the source cited and again at the end of the whole work under references.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Alpha-Thalasemia</td>
<td>A blood disorder that reduces the production and amount of normal hemoglobin. This prevents oxygen from reaching the body's tissues. It causes shortage of red blood cells (anemia), which can cause pale or yellowing of the eyes and skin (jaundice), weakness, fatigue, bone changes such as overgrowth of the upper jaw and an unusually prominent forehead, and more serious complications. ¹</td>
</tr>
<tr>
<td>Beta-Thalassaemia</td>
<td>An inherited blood disorder that reduces the production of hemoglobin caused by reduced or absent synthesis of the beta chains of hemoglobin resulting in variable phenotypes ranging from severe anemia to clinically asymptomatic individuals. Patients have one copy of the hemoglobin S gene and one copy of a hemoglobin beta-thalassemia gene.²</td>
</tr>
<tr>
<td>Beta-Plus Thalasemia</td>
<td>A mild form of sickle cell disease in which the red blood cells contain abnormal hemoglobin called hemoglobin S or sickle hemoglobin in addition to a small amount of the normal hemoglobin called hemoglobin A. The red blood cells have a defect called beta-plus thalassemia, which results in cells which are small in size and more pale than usual.³</td>
</tr>
<tr>
<td>Beta-Zero Thalasemia</td>
<td>This condition is similar to sickle cell anemia. In addition, red blood cells have a defect called thalassemia, which results in cells that are small in size and more pale than usual. The red blood cells are somewhat small, pale, and misshapen. Some may appear sickled or banana shaped.⁴</td>
</tr>
</tbody>
</table>

¹ Alpha-Thalasemia  
² Beta-Thalasemia  
³ Beta-Plus Thalasemia  
⁴ Beta-Zero Thalasemia
| **Carrier** | One who inherits only one gene for a genetic problem like sickle cell. Usually there are no symptoms, and the carrier will never have the disease. Two carriers have a 25% risk of having a child with disease.  

5 |  
| **Chromosomes** | The DNA code for all the parts of the human body. Each person has 46 individual chromosomes in cells, divided into 23 pairs donated from each parent. Chromosome 11 is where the sickle cell mutation occurs.  

6 |  
| **Delta-Beta Thalassemia** | A deletion, decrease or absent of both the delta- and beta-globin chains on chromosome 11. It increases gamma-genes which increases the amount of hemoglobin F production. It exists in both heterozygous and homozygous forms. The symptoms are mild to moderate depending on the severity of the disease and can include mild, hypochromic anemia, slight hepatomegaly and/or splenomegaly and occasional bone changes due to the erythroid hyperplasia. Patients rarely require treatment, but blood transfusions may be necessary in certain cases.  

7 |  
| **Drepanocytosis Genetic** | Occurrence of drepanocytes (sickle cells) in the blood. From the Greek “drepnos” meaning “sickle”) is a hereditary disease and is characterized by the alteration of hemoglobin, a protein of the transport of oxygen in the blood.  

8 |  
| **Hemoglobin** | The protein substance inside the red blood cells that holds and releases oxygen. This is where the sickle mutation occurs.  

9 |  
| **Hemoglobin AS** | Sickle cell trait (AS) is not a type of sickle cell disease. It is an inheritance of a normal A hemoglobin gene and S hemoglobin gene. Individuals with sickle cell trait are generally healthy.  

10 |  
| **Hemoglobin C Disease (SC)** | This disease occurs when a person has both hemoglobin S and hemoglobin C and no normal or adult hemoglobin. Children inherit SC from both parents as a recessive genetic disorder. Persons with SC disease sometimes may have serious health problems that include: infection of the blood (septicemia), sudden enlargement of the spleen, swelling of hands and feet, fever, increased infections, leg ulcers, gallstones, vision problems, yellow skin, organ damage and kidney failure. SC disease occurs in all races, but mostly common among people of African, Caribbean and South American ancestry.  

11 |  
| **Hemoglobin D Disease** | A different substitution of the beta globin gene. It interacts with

---

5 Carrier  
6 Chromosomes  
7 Delta-Beta Thalassemia  
8 Drepanocytosis Genetic  
9 Hemoglobin  
10 Hemoglobin AS  
11 Hemoglobin C Disease (SC)
| (SD) | the sickle hemoglobin gene. Individuals with this disease have moderately severe anemia and occasional pain episodes. Populations that have a high frequency of this disease are those of Asian and Latin American descents.  
Hemoglobin H Disease (HbH) | HbH is a moderate to severe form of alpha-thalassemia and it is characterized by pronounced microcytic hypochromic hemolytic anemia. HbH disease causes the red blood cells to break down faster than usual. Other complications include: an enlarged spleen, gallstones, increased risk for infections, jaundice (yellowing of the skin) and leg ulcers. HbH disease may first be noticed in childhood or in early adult life when the anemia and hepatosplenomegaly are noted. It is predominantly seen people in Southeast Asia, the Middle East and the Mediterranean.  
Hemoglobin Electrophoresis | The blood test that identifies the type of hemoglobins present in the red blood cells.  
Hemoglobin O Disease (SO) | Another type of substitution in the beta globin gene, also interacts with sickle hemoglobin. Individuals with this disease can have symptoms of sickle cell anemia. Populations that have a high frequency of this disease are those of Arabian, North African and Eastern Mediterranean descents.  
Hemoglobinopathy | A term used to describe disorders caused by the presence of abnormal hemoglobin reproduction in the blood.  
Hemoglobin SS Disease (SS) | This is the most common form of sickle cell disease. When a child inherits two substitution beta globin genes from both parents, the child has SS. That is, two copies of the hemoglobin S gene. Hemoglobin SS Disease is the most chronic hereditary blood disease, in which abnormal hemoglobin causes red blood cells to become sickle-shaped and nonfunctional, characterized by enlarged spleen, chronic anemia, lethargy, weakness, joint pain, blood clot formation, pneumonia, stroke, blood in urine, leg ulcers, gallstones, vision problems, jaundice, organ damage, kidney failure, painful erections, problems during pregnancy and sudden death. Populations that have a high frequency of sickle cell anemia are those of African and Indian descents. |

12 Hemoglobin D Disease (SD)  
13 Hemoglobin H Disease (HbH)  
14 Hemoglobin Electrophoresis  
15 Hemoglobin O Disease (SO)  
16 Hemoglobinopathy  
17 Hemoglobin SS Disease (SS)
<table>
<thead>
<tr>
<th><strong>Mendelian or Mendelian Inheritance</strong></th>
<th>Inheritance of characters specifically transmitted by genes in accord with Mendel's laws. Alleles of different genes separate independently of one another when gametes are formed. Different traits are inherited independently of one another.(^\text{18})</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sickle Cell Anemia (SCA, SS)</strong></td>
<td>The most common form of sickle cell disease. Sickle cell anemia is the result of the inheritance of the gene for sickle hemoglobin S from both parents.(^\text{19})</td>
</tr>
<tr>
<td><strong>Sickle Cell Disease (SCD)</strong></td>
<td>It is a form of blood anemia in which sufferers are born with an irregular shaped red blood cell that dispense itself faster than normal shaped red blood cell. For instance, while an average human red blood cell last for about 120 days before another one is produced, a sickled red-blood cell last for only about 54-60 days leading to anemic situation in sufferers.(^\text{20})</td>
</tr>
<tr>
<td><strong>Sickled Cells</strong></td>
<td>In persons with sickle cell disease, hemoglobin S in red blood cells stick to one another and cause the red cells to become crescent or sickle shaped. Sickled cells cannot pass easily through tiny blood vessels.(^\text{21})</td>
</tr>
<tr>
<td><strong>Sickle Cell Trait (AS)</strong></td>
<td>The inheritance of one gene for normal hemoglobin (A) and one gene for sickle hemoglobin (S). A person who has sickle cell trait AS is a carrier of the sickle gene, does not have the disease, and is generally not affected by the sickle hemoglobin.(^\text{22})</td>
</tr>
<tr>
<td><strong>Sickle Crisis or Pain Episode</strong></td>
<td>Pain in the bones and muscles where blood flow has been blocked by sickled red blood cells. Represents an instance of pain experience by sufferers due to lack of tissue oxygenation. Pain is most often felt in the arms, legs, back, and abdomen, and may last only a few hours or as long as a week or two. The number of pain events a person has may vary greatly.(^\text{23})</td>
</tr>
<tr>
<td><strong>Thalassemia</strong></td>
<td>A blood disorder passed down through families in which the body makes an abnormal form of hemoglobin, the protein in red blood cells that carries oxygen. Thalassemia results in excessive destruction of red blood cells, which leads to anemia.(^\text{24})</td>
</tr>
<tr>
<td><strong>Vaso-Occlusive Crisis</strong></td>
<td>A common painful complication of sickle cell anemia in adolescents and adults. It is a form of sickle cell crisis. It occurs when the circulation of blood vessels is obstructed by sickled red blood cells, causing ischemic injuries.(^\text{25})</td>
</tr>
</tbody>
</table>

\(18\) Mendelian or Mendelian Inheritance
\(19\) Sickle Cell Anemia (SCA, SS)
\(20\) Sickle Cell Disease (SCD)
\(21\) Sickled Cells
\(22\) Sickle Cell Trait (AS)
\(23\) Sickle Crisis or Pain Episode
\(24\) Thalassemia
\(25\) Vaso-Occlusive Crisis
APPENDIX B

Human Subject Protection Training Certificate

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Olatundun Abimbola successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 06/03/2012

Certification Number: 930237
APPENDIX C

Permission Letter To Conduct Interview

Date:
Name of [Name of Organization/Support/Group/Community Group]:
Address:
City, State, Zip:

Institution: Northeastern University, College of Professional Studies
Student Investigator: Olatundun Abimbola

Title of Research Study: Education and Sickle Cell Anemia: A Narrative Study of the Educational Experiences of Individuals Living with Sickle Cell Anemia

I am a doctoral candidate in the College of Professional Studies at Northeastern University, Boston Massachusetts. I am conducting a study with the purpose of exploring and describing the educational experiences of individuals living with Sickle Cell Anemia (SCA). I am inviting persons: (1.) Diagnosed as having SCA, (2.) Have earned a bachelor’s, a master’s and/or a doctorate degree, (3.) Have reached the age of 25 years or older, and (4.) Ready and willing to take part in the study. This study has been approved by Northeastern University’s Institutional Review Board for research ethics (IRB# CPS15-03-11).

I received your [name] from_______, and I would be most grateful if you could assist in identifying or providing a list of individuals who meets the above criteria. The study will consist of two open-ended interviews, which may be conducted either by Skype® or telephone. The first interview will focus on life history and personal experiences in relation to the topic (this part will take approximately 60 to 90 minutes). The second interview will allow the participant to reflect upon the meaning of the experiences from the first interview (this part will take approximately 60 minutes). Interviews will be audio recorded and participants will be provided with copies of the interview transcripts for their review if desired before the final version is completed.

I appreciate your consideration, and I sincerely hope that you will strongly consider my request in this important effort to document Education and Sickle Cell Anemia: A Narrative Study of the Educational Experiences of Individuals Living with Sickle Cell Anemia. I hope that you can assist me in identifying one or more potential participants who meet the above stated criteria. Should anyone be willing to learn more about the study, please send their contact information, including their names, phone numbers and email addresses to me via email at abimbola.o@husky.neu.edu or by phone at 617-922-1977. Should you have any questions or concerns, please do not hesitate to contact me. Thank you in advance for your time and consideration. I am looking forward to hearing from you.

Sincerely,

Olatundun Abimbola
APPENDIX D

Letter of Invitation to Participate in Research (Recruitment Letter)

Volunteers Wanted for a Research Study!

Date:

Name of potential participant:
Address:
City, State, Zip:

Re: Education and Sickle Cell Anemia: A Narrative Study of the Educational Experiences of Individuals Living with Sickle Cell Anemia

Dear (Name of potential participant):

I am writing to inform you about an opportunity to participate in an exciting study about the personal experiences of persons with Sickle Cell Anemia (SCA). This study is being conducted by Olatundun Abimbola, a doctoral candidate in the College of Professional Studies at Northeastern University, Boston Massachusetts. This study has been approved by Northeastern University’s Institutional Review Board for research ethics (IRB# CPS15-03-11). The purpose of this study is to explore and describe the educational experiences of individuals living with SCA. Another important justification for this research stems from my personal interest as a person also diagnosed with SCA. I am inviting persons:

1. Diagnosed as having SCA.
2. Have earned a bachelor’s, a master’s and/or a doctorate degree.
3. Have reached the age of 25 years or older.
4. Ready and willing to take part in the study.

The study will consist of two open-ended interviews, which may be conducted either by Skype® or telephone. Thus, location will not prohibit anyone wishing to be interviewed from participating. The first open-ended interview will focus on your life history and personal experiences in relation to the topic (this part will take approximately 60 to 90 minutes). The second open-ended interview will allow you to reflect upon the meaning of the experiences from the first interview (this part will take approximately 60 minutes).

If you are interested in learning more about the study, please review the attached PDF files, complete the materials and email me at abimbola.o@husky.neu.edu. You can also contact me directly by phone at 617-922-1977.

In addition, if you know other individuals such as, friends and/or family members who may like to take part in the study or learn more, please feel free to forward this letter to them along with the attached files.
It is important to know that your participation in the study is completely voluntary. Although I hope you will join me and participate. If you choose to take part, please be assured that your responses are confidential and will be managed as such. I will not release, share with others or use any information that can be linked to you in the published results. If you choose to participate you may choose to opt out at any time and you may choose any of the interview questions that you do not wish to answer.

You do not have to respond if you are not interested in the study. If you do not respond, I will not contact you. You can simply disregard this or email me back in order to avoid receiving another email should you wish not to participate in the study.

Thank you in advance for your time and consideration. Your participation will help enhance our understanding about SCA. I look forward to hearing from you. Please feel free to email me with any questions.

Sincerely,

Olatundun Abimbola
APPENDIX E

Application for Institutional Review Board (IRB) Approval

APPLICATION FOR APPROVAL FOR USE OF HUMAN PARTICIPANTS IN RESEARCH

For NU IRB use:

Date Received: ___________________________ NU IRB No. ________________

Review Category: ________________________ Approval Date ________________

APPLICATION FOR APPROVAL FOR USE OF HUMAN PARTICIPANTS IN RESEARCH

Before completing this application, please read the Application Instructions and Policies and Procedures for Human Research Protections to understand the responsibilities for which you are accountable as an investigator in conducting research with human participants. The document, Application Instructions, provides additional assistance in preparing this submission.

Incomplete applications will be returned to the investigator. You may complete this application online and save it as a Word document.

If this research is related to a grant, contract proposal or dissertation, a copy of the full grant/contract proposal/dissertation must accompany this application.

Please carefully edit and proof read before submitting the application. Applications that are not filled out completely and/or have any missing or incorrect information will be returned to the Principal Investigator.
REQUIRED TRAINING FOR RESEARCH INVOLVING HUMAN SUBJECTS

Under the direction of the Office of the Vice Provost for Research, Northeastern University is now requiring completion of the NIH Office of Extramural Research training for all human subject research, regardless of whether or not investigators have received funding to support their project.

The online course titled "Protecting Human Research Participants" can be accessed at the following url: http://phrp.nihtraining.com/users/login.php. This requirement will be effective as of November 15, 2008 for all new protocols.

Principal Investigators, student researchers and key personnel (participants who contribute substantively to the scientific development or execution of a project) must include a copy of their certificate of completion for this web-based tutorial with the protocol submission.

A. Investigator Information

Principal Investigator (PI cannot be a student) __ Dr. Al D. McCready

Investigator is: NU Faculty ____ X ____ NU Staff _______ Other _______

College: Choose an item. __ Northeastern University College of Professional Studies ___

Department/Program ______ College of Professional Studies/Doctor of Education

Address ______ 41 BV College of Professional Studies, Boston MA 02115

Office Phone _____ 203-698-2699 _____ Email ______ a.mccready@neu.edu

Is this student research? YES ____ X ____ NO _____ If yes, please provide the following information:

Student Name ______ Olatundun Abimbola ___ Anticipated graduation date September 25, 2015

Undergrad ____ MA/MS ____ PhD ____ AuD ____ X ____ EdD ____ DLP ____ Other Degree Type

College: Choose an item. __ Northeastern University College of Professional Studies ___

Department/Program ______ College of Professional Studies/Doctor of Education
Full Mailing Address ________________________________________________________________

Telephone     617-922-1977  Primary Email       abimbola.o@husky.neu.edu

Cell phone    617-922-1977      Secondary Email    oabimbola@aol.com

B. Protocol Information

Title: Education and Sickle Cell Anemia: A Narrative Study of the Educational Experiences of Individuals Living with Sickle Cell Anemia

Projected # subjects  3-4

Approx. begin date of project  January 7, 2013  Approx. end date  June 27, 2015

It is the policy of Northeastern University that no activity involving human subjects be undertaken until those activities have been reviewed and approved by the University's Institutional Review Board (IRB).

- Anticipated funding source for project (or none)  NONE

Has/will this proposal been/be submitted through:
  - NU’s Office of Research Administration and Finance (RAF)  NO
  - Provost  NO
  - Corp & Foundations  NO

C.

<table>
<thead>
<tr>
<th>Will Participants Be</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children (&lt;18)</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Northeastern University Students?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Institutionalized persons?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Prisoners?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Cognitively Impaired Persons?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Non or Limited English Speaking Persons?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>People Living outside the USA?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Pregnant Women/Fetuses?</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does the Project Involve:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Removal?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Investigational drug/device?</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Audiotapes/videotapes?</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

|
D. What are the goals of this research? Please state your research question(s) and related hypotheses.

The professional goals of the study are: (1) to explore and describe the educational experiences of individuals living with SCA; (2) to understand the challenges that persons with SCA are faced with on a continuing basis and (3) to identify common themes and patterns within the participants’ description of their experiences. The intellectual goals of the study are: (1) to gain new insights and enhanced understanding into the meaning of the experiences of persons with SCA and (2) to use the researcher’s personal and professional experiences, her specific recollection and her current understanding of herself as a SCA patient and sufferer to provide another approach to address the topic.

An important justification for the interest in this research stems from the various experiences the researcher have had, as a SCA patient and in the K-12 teaching and school administrative realm. These experiences have allowed the researcher to gain a more comprehensive understanding of the realities that people with challenging health conditions face as a result of disability or impairment.

The following question guides the direction of this research study: What are the educational experiences of individuals living with SCA?

There are no hypotheses for this narrative study.

E. Provide a brief summary of the purpose of the research in non-technical language.

The purpose of this research is to explore and describe the educational experiences of individuals living with SCA.

The study of those with SCA is complex, yet relevant to the experiences of other students with this disease and to a wide range of students with other chronic illnesses in the American school system. This study will give a voice to persons with SCA to have their opinions and feelings heard.

F. Identify study personnel on this project. Include name, credentials, role, and organization affiliation.

Principal Investigator – Dr. Al D. McCready, EdD; Northeastern University faculty located in Northeastern University College of Professional Studies – will have full access to data.
G. Identify other organizations or institutions that are involved. Attach current Institutional Review Board (IRB) approvals or letters of permission as necessary.

Beyond Northeastern University, no other organizations or institutions will be formally involved with the process of this research study; therefore, IRB approval is not required from any other organizations or institutions.

H. Recruitment Procedures

Describe the participants you intend to recruit. Provide all inclusion and exclusion criteria. Include age range, number of subjects, gender, ethnicity/race, socio-economic level, literacy level and health (as applicable) and reasons for exempting any groups. Describe how/when/by whom inclusion/exclusion criteria will be determined.

Participants will consist of 3 to 4 people who have reached the age of 25 years or older and have gone through the systems of higher education.

Participants will be adults diagnosed as having SCA, who have earned a bachelor’s, a master’s and/or a doctorate degree and ready and willing to take part in the study.

Recruitment of participants for the study will be based on the selection of individuals who meet the above mentioned predetermined set of criteria. After the researcher has obtained approval from the IRB, the researcher will contact trusted organizations, community and support groups, friends and family members to gain access to names of individuals with SCA who are willing to participate in the study.

If the researcher seeks an organization, a community or a support group in order to attempt to access a list of potential participants with SCA, the researcher will obtain the necessary permission from those organizations and/or groups to access their contact information.

Describe the procedures that you will use to recruit these participants. Be specific. How will potential subjects be identified? Who will ask for participation? If you intend to recruit using letters, posters, fliers, ads, website, email etc., copies must be included as attachments for stamped approval. Include scripts for intended telephone recruitment.

Access to participants for the study will be secured by contacting prospective participants via email. A recruitment letter (Appendix D) will be sent via email to these potential participants. In the letter, potential participants will be informed of the nature and purpose of the study, information about the topic, and its significance. The researcher will request that those interested in volunteering as participants contact her via email or by telephone as listed on the recruitment and consent letter (Appendix F).
The recruitment letter (Letter of Invitation to Participate in Research – Appendix D) will include the Informed Consent Form (Appendix F) as an attachment.

**What remuneration, if any, is offered?**

Not applicable. Remuneration will not be offered to participants in the study.

1. **Consent Process**

Describe the process of obtaining informed consent*. Be specific. How will the project and the participants’ role be presented to potential participants? By whom? When? Where? Having the participant read and sign a consent statement is done only after the researcher provides a detailed oral explanation and answers all questions. Please attach a copy of informed consent statements that you intend to use, if applicable. Click here for consent form templates.

If your study population includes non-English speaking people, translations of consent information are necessary. Describe how information will be translated and by whom. You may wait until the consent is approved in English before having it translated.

Informed consent will be obtained from participants in order to conduct the research. Each potential participant will be given a detailed oral explanation of the scope of the project during the initial intake meeting (see Appendix G). Informed consent will be read and reviewed with each potential participant. The researcher will explain to each participant that there will be no risks, inconveniences or discomforts associated with participating in the study. Potential participants will be assured that their participation is voluntary should they decide to participate in the study. This means they may elect not to be part of the study and also may withdraw from the study at any time.

Potential participants will be informed that they will be sent consent to participate form via email. Each participant will be asked to review and complete the form, and to email the electronically signed form to the researcher at her Northeastern University email address: abimbola.o@husky.neu.edu. Please see attached Appendix F for the consent information. Signed consents will be returned to the researcher before any interview begins.

The researcher will not be interviewing non-English speaking people; therefore, translations of consent information are not necessary.

The researcher will not be interviewing non-English speaking people; therefore

If your population includes children, prisoners, people with limited mental capacity, language barriers, problems with reading or understanding, or other issues that may make them vulnerable or limit their ability to understand and provide consent, describe special procedures that you will institute to obtain consent appropriately. If participants are potentially decisionally impaired, how will you determine competency?

Not applicable.
If incomplete disclosure during the initial consent process is essential to carrying out the proposed research, please provide a detailed description of the debriefing process. Be specific. When will full disclosure of the research goals be presented to subjects (e.g., immediately after the subject has completed the research task(s) or held off until the completion of the study’s data collection)? By whom? Please attach a copy of the written debriefing statement that will be given to subjects.

Not applicable.

J. Study Procedures

Provide a detailed description of all activities the participant will be asked to do and what will be done to the participants. Include the location, number of sessions, time for each session, and total time period anticipated for each participant, including long term follow up.

Participants will be asked to complete a questionnaire, in regards to their background (see Appendix H). The intent is to gather basic background information to create a summary table and a written description that will be associated with each participant in the study. This should take each participant between 5 to 10 minutes to complete.

Participants will be interviewed two separate times. During the first interview, participants will be asked a series of questions that focus on their life history and personal experience in relation to SCA. The second interview will focus on some of the information already provided by the participants and what each participant makes of certain things they spoke about during the first interview. The first interview will last between 60 to 90 minutes and the second interview should last just about 60 minutes. As part of the second-interview discussion, each participant will be asked to email the researcher in advance 1 or 2 artifacts that describe or that represent their personal experiences with SCA. Participants will also be asked to talk about the artifacts based on their past or present moment experiences with SCA and how these artifacts may have influenced or helped shape their educational experiences as a person living with SCA. Participants will be asked to blank out their names or any other identifying marks on the documents to protect their identities as a participant in the study. The collection of documents will further be used by the researcher to elicit and capture additional data from each participant’s point of view (see Appendix I).

Interviews will be conducted via Skype® or telephone at a time that is convenient for each participant. The two interviews will take place within a 3 to 7 day period.

Who will conduct the experimental procedures, questionnaires, etc? Where will this be done? Attach copies of all questionnaires, interview questions, tests, survey instruments, links to online surveys, etc.

Both interviews will be conducted by the researcher (Olatundun Abimbola). The study will consist of two open-ended interviews, which may be conducted either by Skype® or telephone.
Copies of all procedure, questionnaires and interview questions are attached (see appendices H and I).

K. Risks

Identify possible risks to the participant as a result of the research. Consider possible psychological harm, loss of confidentiality, financial, social, or legal damages as well as physical risks. What is the seriousness of these risks and what is the likelihood that they may occur?

The interview questions will ask participants to reflect upon their personal experiences, perspectives and feelings in relation to being a person living with SCA. If at any time during the interview process participants feel uncomfortable responding to any of the questions that are being asked, they may decline that question. Participants can also choose to discontinue participation in the study at any time. There are no foreseeable risks, harms, discomforts associated with the study. This study will not harm participants; and any information collected will not potentially damage, hurt, harm or cause discomforts to participants.

The probability of psychological harm to participants in this research study is essentially non existence. However, if a participant becomes emotionally upset or distressed (e.g., cry, shake, tremble, sweat or seem depressed), the researcher will change the line of questioning. If it becomes evident that changing the line of questioning was to no avail, then the researcher will terminate the interview. The researcher will inform the participant that if he or she would like to continue the interview at a later date to contact the researcher. After 2 or 3 days, the researcher will contact the participant to inquire of their well-being. The researcher will not try to entice the participant to continue the interview unless he or she suggests it. If the participant does not suggest completion of the interview, the researcher will then endeavor to contact another potential participant.

Every effort possible will be made to ensure confidentiality, and no other risks (financial, social, physical or legal damages, etc.) seem likely based on participation in the study.

Describe in detail the safeguards that will be implemented to minimize risks. What follow-up procedures are in place if harm occurs? What special precautions will be instituted for vulnerable populations?

There are no anticipated or foreseeable risks associated with participation this study. At all times, the researcher will follow the established guidelines for protecting of human participants in a research study.

The probability of harm to participants as a result of participation in this research is almost non existence. If at any time a participant feels uncomfortable answering a particular question or would like to withdraw for any reason, he or she may do so (as stated in the Informed Consent Form – Appendix F).

The researcher will implement the necessary safeguards at all times to protect all participants.
L. Confidentiality

Describe in detail the procedures that will be used to maintain anonymity or confidentiality during collection and entry of data. Who will have access to data? How will the data be used, now and in the future?

Only the researcher’s advisor, Dr. Al D. McCready and the researcher, Ms. Olatundun Abimbola will have access to data. Both interviews will be audio-recorded. No reports or publications will use information that can identify participants in any way or any individual as being part of the project.

Confidentiality will be further maintained in the following manner: No names, home, work or email addresses will be associated with any interview information. Any information that could reveal the identity of participants will be altered to maintain their confidentiality and to protect their privacy. The recording of the interviews will not be labeled with participant’s name, home, work or email address, but rather a pseudonym (code name).

The data gathered from the interviews will be used for the researcher’s doctoral thesis project, and potentially for her use in future books, academic journals, and other publications relating to the topic. Even in these additional potential instances, identifying information will always be kept confidential for all participants.

How and where will data be stored? When will data, including audiotapes and videotapes, be destroyed? If data is to be retained, explain why. Will identifiers or links to identification be destroyed? When? Signed consent documents must be retained for 3 years following the end of the study. Where and how will they be maintained?

Data will be stored and kept in a highly secured location at all times. Laptop computer when not being used for interviews will be kept in secured location to prevent unauthorized access to computer files. All data will be password-protected, making them inaccessible to others. Furthermore, to ensure that participants’ confidentiality remains intact, pseudonyms (code names) will be used in place of identifying information so that participants’ identities cannot be recognized by others.

All of the study-related data files, including audio recordings and hard-copy materials containing participants’ information will be permanently deleted and destroyed after the completion of the study in a consistent high security manner for reasons of confidentiality and privacy of the research participants. Audio recordings will be destroyed 2 months after completing the transcriptions.

Any signed consent documents along with other important and sensitive documents will remain intact and will be securely stored under lock and key in a location inaccessible to others. Such documents will be destroyed 3 years subsequent the completion of the study. The data will be used solely for the researcher’s doctoral thesis project, and may possibly be used for future lectures, seminars, presentations, books, documentaries, academic journals and other publications relating to the topic in this study. In these instances, of course, confidentiality will
still be applied at all times for all participants and their information will continue to be stored in a secured manner.

**M. If your research is HIPAA-protected, please complete the following;**

**Individual Access to PHI**

Describe the procedure that will be used for allowing individuals to access their PHI or, alternatively, advising them that they must wait until the end of the study to review their PHI.

Not applicable.

**N. Benefits**

What benefits can the participant reasonably expect from his/her involvement in the research? If none, state that. What are potential benefits to others?

There will be no direct benefits to participants for taking part in the research. However, information learned may benefit other people with the disease and may help raise awareness of this global medical issue.

A successful completion of this research will allow the researcher to complete a Doctor of Education program at Northeastern University.

**O. Attachments**

Identify attachments that have been included and those that are not applicable (n/a).

| Apx | D Copy of fliers, ads, posters, emails, web pages, letters for recruitment * |
| Apx | G Scripts of intended telephone conversations* |
| Apx | K Copies of IRB approvals or letters of permission from other sites |
| Apx | F Informed Consent Form(s)* (see our templates for examples) |
| N/A | Debriefing Statement* |
| Apx | I Copies of all instruments, surveys, focus group or interview questions, tests, etc. |
| Apx | J Signed Assurance of Principal Investigator Form (required) |
| Apx | B NIH Human Subject Training Certificate(s) (required if not already on file at HSRP) |

*(Approved forms must be stamped by the IRB before use)*

**P. Health Care Provision During Study**

Please check the applicable line:

____X____ I have read the description of HIPAA “health care” within Section 4 of the Policies & Procedures for Human Research Protection. I am not a
HIPAA-covered health care provider and no health care will be provided in connection with this study.

I am a HIPAA-covered health care provider or I will provide health care in connection with this study as described in Section 4 of the Policies & Procedures for Human Research Protection. This health care is described above under “Study Procedures,” and the Informed Consent and Health Information Use and Disclosure Authorization form will be used with all prospective study participants.

If you have any questions about whether you are a HIPAA-covered health care provider, please contact Nan C. Regina, Director, Human Subject Research Protection at n.regina@neu.edu or (617) 373-4588.

Completed applications should be submitted to Nan C. Regina, Director, Human Subject Research Protection with the exception of applications from faculty and students of the College of Professional Studies, which should be submitted to Kate Skophammer, IRB Coordinator for CPS.

Nan C. Regina, Director
Northeastern Univ., Human Subject Research Protection
360 Huntington Ave., Mailstop: 960 Renaissance Park
Boston, MA 02115-5000
Phone: 617.373.4588; Fax: 617.373.4595
n.regina@neu.edu

CPS applications only
Kate Skophammer, IRB Coordinator
Northeastern Univ., College of Professional Studies
Phone: 617.390.3450;
k.skophammer@neu.edu

The application and accompanying materials may be sent as email attachments or in hard copy. A signed Assurance of Principal Investigator Form may be sent via fax or in hard copy.
Informed Consent to Participate in a Research Study

You are being invited to take part in a research study. This form will tell you about the research. You may ask the researcher any questions that you have. When you are ready to make a decision, you may tell the researcher if you want to participate or not. If you decide to participate, the researcher will ask you to sign this statement and will give you a copy to keep for your record.

Why am I being asked to take part in this research study?

You are being asked to be in the research study because you are identified as a person living with Sickle Cell Anemia (SCA) and who has also completed a bachelor’s, a master’s and/or a doctorate degree.

Why is this research study being done?

The research study is being done to explore and describe the educational experiences of individuals living with SCA.

What will I be asked to do?

If you decide to take part in this research study, you will be asked to participate in two open-ended interviews conducted by Olatundun Abimbola, a student investigator at Northeastern University. In the first interview you will be asked questions about your personal experiences in relation to the topic. The second interview will allow you to reflect upon the meaning of your experiences. At the end of the second interview, if the researcher comes across a need to ask any
follow-up questions or if clarifications are needed in regard to any of your responses, the researcher may contact you (you may decline and still be included in the study). Both interviews will be audio-recorded for accuracy and will be transcribed verbatim. Transcripts of the two interviews along with the researcher’s initial codes and interpretations will be emailed to you within a month after the second interview. You will have one week to present any feedback, alterations or corrections to these documents, should you chose to do so.

Where will this take place and how much of my time will it take?

You will be interviewed two times through your favored setting (Skype® or telephone), and at a time that is convenient for you. You should aim to be in a relaxed, comfortable space and a private setting. The first interview will last approximately 60 to 90 minutes, and the second approximately 60 minutes. The two interviews will take place within a 3 to 7 day period.

Will there be any risk or discomfort to me?

During the two interviews, the researcher will ask you to reflect upon your personal experiences in relation to being a person living with SCA. If you feel uncomfortable responding to any of the questions that are being asked, you may decline that question. You may also choose to discontinue participation in the study at any time.

Every effort possible will be made to ensure confidentiality, and no other risks (financial, social, physical, etc.) seem likely based on your participation in the research study.

Will I benefit by being in this research?

There will be no direct benefit to you for taking part in this research. However, the information learned may benefit other people with the disease and may help raise awareness about this global medical issue.

Who will see the information about me?

Your part in the study will be confidential. Only you, the student investigator’s advisor, Dr. Al D. McCready and the student investigator, Ms. Olatundun Abimbola will see the information. Only you and the student investigator, Ms. Olatundun Abimbola will be present during the interviews. The interviews will be audio-recorded. The researcher will sign a Transcriber Confidentiality Statement and have you initial it. No reports or publications will use information that can identify you in any way or any individual as being part of this study.

Confidentiality will be maintained in the following manner:
1. Your names, home, work or email addresses will not be associated with any interview information.
2. Any information that could reveal your identity and personal information will be altered to protect your confidentiality.
3. Recording of the interview will not be labeled with your name, home, work or email address, but rather a pseudonym (code name).
4. All of the study-related data files will be stored in a secured location and password protected.
5. Audio-recordings will be destroyed within two months of completing the transcriptions.

The data gathered from these interviews will be used for the researcher’s doctoral thesis project, and potentially for additional use in the researcher’s future lectures, seminars, presentations, books, documentaries, academic journals and other publications relating to the topic in this study. Even in these additional potential instances, your identity and personal information will always be kept confidential.

<table>
<thead>
<tr>
<th>If I do not want to take part in the study, what choices do I have?</th>
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You have every right to choose not to participate in the study.

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<th>What will happen if I suffer any harm from this research?</th>
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Based on the content and structure of this research, the potential of being harmed in any way is essentially nonexistent. While unlikely, if you become highly emotional, the researcher will recommend the questioning to be terminated at that time.

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<th>Can I stop my participation in this study?</th>
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Yes, your participation in this study is completely voluntary. You do not have to participate if you do not wish to and you can refuse to answer any question. Even if you begin this study, you may quit at any time. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have (as a student, employee, etc).

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<th>Who can I contact if I have questions or problems?</th>
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If you have any questions about the research study, please feel free to contact the researcher at 617-922-1977 (cellular number) or by email at abimbola.o@husky.neu.edu. You may also contact the Principal Investigator, Dr. Al D. McCready at 203-698-2699 (office number), by email at a.mccready@neu.edu or by mail at Northeastern University, Boston MA, 02115, attn: Dr. Al D. McCready.

<table>
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<th>Who can I contact about my rights as a participant?</th>
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</table>
If you have any questions about your rights as a participant, you may contact Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park, Northeastern University, Boston, MA 02115. Tel: 617.373.4588, Email: n.regina@neu.edu. You may call anonymously if you wish.

Will I be paid for my participation?

No, you will not be paid for your participation in this research study.

Will it cost me anything to participate?

No, it will not cost you anything to participate in this research study.

Is there anything else I need to know?

You must meet the following criteria:

1. Diagnosed as having Sickle Cell Anemia.
2. Has earned a bachelor’s, a master’s and/or a doctorate degree.
3. Has reached the age of 25 years or older.
4. Ready and willing to take part in the study.

By signing this document, you are consenting for the interviews to be audio-recorded.

Once the entire study is complete, an electronic copy can be sent to you via email should you wish to receive a copy.

I agree to take part in this research study.

Signature of person agreeing to take part __________________________________________ Date ____________

Printed name of person above ____________________________________________________