SICKLE CELL DISEASE, EDUCATION, AND LATER LIFE OUTCOMES

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ABSTRACT

Melanie McCabe: Sickle Cell Disease, Education, and Later Life Outcomes
(Under the direction of Rune J. Simeonsson)

The goal of the study was to investigate the impact of education on life outcomes of adults with sickle cell disease (SCD) while accounting for personal and disease variables. Five hierarchical regressions were conducted to determine if gender, educational attainment, and disease severity, entered sequentially, were predictive of later life outcomes in adults with SCD. Outcomes assessed were depressive symptomatology, pain intensity level, satisfaction with support in relationships, income, and employment status in adults with SCD. Models predicting income and employment status were significant when educational attainment and disease severity were included in the prediction. Study findings indicate that educational attainment accounts for a significant amount of variance in later life outcomes for individuals with SCD. Specific recommendations for support of individuals with SCD are made for school psychologists.
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CHAPTER I: INTRODUCTION

Sickle Cell Disease (SCD) is a disorder of the blood that until recently, due to truncated life expectancies compared to the general population, has been conceptualized primarily as a childhood disease (Chaine, Neonato, Girot, & Aractingi, 2001). National efforts in public education and health as well as advances in hematological and medical sciences have successfully promoted health behaviors and extended lifespan for patients with this complicated disease. For example, hydroxyurea, a medication borrowed from oncology that is effectively and commonly prescribed for the management of SCD has resulted in individuals living into adulthood and improved quality of life during their aging (Figueiredo, 2013; Pells et al., 2005). The use of hydroxyurea, combined with better screening at birth and adult education, has extended the life expectancy of many patients today into their 40s and for a few patients, into their 50s and 60s.

With the widespread use of pharmacological interventions, individuals with SCD are now able to participate in a traditional education, engage in developmentally appropriate activities, and even enter the workforce as adults. Despite these advances, individuals with SCD still experience chronic symptoms related to inconsistent eating patterns, elevated body mass index, and frequent pain crises, among other ailments. Consequently, though patients with SCD may be living longer than ever, their quality of life (QOL) suffers (Pells, 2005).
Though individuals with SCD may engage in recreational and schooling activities, their participation often requires modifications or additional supports. Examples of modification include increased access to additional drinking water during physical activity and access to restrooms due to increased water consumption. In addition to physical accommodations, an individual with SCD may also require academic accommodations or improved access to educational materials. SCD has been shown to impact individuals in a variety of domains, including cognition, psychosocial functioning, and medical management; the effects of the aforementioned deficits can be observed even in school-aged children. Recent studies have shown that the experience of children with SCD varies from the experience of typically developing children in a number of ways. Children with SCD tend to experience pain crises, medical complications of SCD-related brain trauma, and frequent absences from school because of medical appointments for preventative and reactive treatment (Schatz, Brown, Pascual, Hsu, & DeBaun, 2001).

Within the healthcare community, it is well known that children and adolescents with SCD can experience an array of complications with negative implications for cognition and academic performance (Schatz & Roberts, 2005). In the past decade, the impact of SCD on students in academic settings has become a prominent topic of research (Schatz et al., 2001). Students with SCD have been found to experience difficulties in psychosocial adjustment that can lead to lower levels of social support and higher levels of depression (Hasan, Hashmi, Alhassen, Lawson, & Castro, 2003; Todd, Green, Bonham, Haywood, & Ivy, 2006). Students with SCD and psychosocial difficulties also report higher levels of pain than those in the general population (Todd et al., 2006). The current study seeks to better understand the experience of this population by exploring the associations among academic attainment,
reports of pain, depressive symptomatology, relationship satisfaction, income, and employment status.

**Study Overview**

The academic impact of SCD in children has been a topic of research for over a decade (Schatz et al., 2001), and a variety of factors have been found to contribute to the academic difficulties experienced by children with SCD. Schatz and Roberts (2005) confirmed the results of earlier studies and found that children with SCD are more likely to drop out of school, suffer from cognitive deficits, and experience complications that interfere with their ability to fully participate in the academic setting. Hasan et al. (2003) found that children with SCD experience psychosocial challenges, and children with psychosocial problems experience more academic difficulties than children without psychosocial problems (Roeser, Eccles, & Strobel, 1998). According to Chang and Romero (2008), children with chronic illnesses like SCD are at greater risk for academic failure due to chronic absences. In other words, whether for developmental or logistical reasons, children with SCD experience a very high risk of academic failure.

A review of the relevant literature did not reveal research specifically assessing the relationship between academic attainment and adult QOL within the SCD population. In order to determine whether such a relationship exists, additional research is needed.

The aim of this study is to investigate if educational attainment is predictive of depression, relational support, annual income, and employment status in adults with SCD. This will be the first study to examine adult outcomes within the SCD population based on the childhood variable of education. The study will include self-reported assessments of the childhood educational variable as a protective factor and adult outcome variables—including
experience of depression, disease severity, perception of support in relationships provided by others, annual income, and employment status—that can be considered indicative of QOL. The aforementioned variables will be used to evaluate the relationship between adult QOL and academic attainment as a protective factor. Many studies document the relationship between academic attainment and QOL in other populations, but to date no studies have examined academic attainment as a predictor for QOL within the SCD population. This study seeks to provide new information regarding the importance of childhood education on later QOL in adulthood. Furthermore, this study will examine educational attainment related to protective factors and adult outcomes, another area where research of SCD is lacking.
CHAPTER II: LITERATURE REVIEW

Childhood Illness in Schools

Chronic illness can be defined as a permanent or long-term medical condition that affects daily functioning (Shaw, Glaser, Stern, Sferdensch, & McCabe, 2010). Identification and management of chronic illnesses in children is often difficult because children lack autonomy from their parents, and their illnesses are reflective of individual as well as family dynamics. Children with chronic illnesses often can be effectively evaluated and identified by parent’s characterization of the child’s activity-limiting physical, mental, or emotional health conditions (Halfon & Newacheck, 2010). Halfon & Newacheck (2010) also indicated that children with chronic illnesses must be conceptualized and treated differently than adults:

Child advocates and pediatric clinicians have long argued that children are not little adults and that the definition, conceptualization, and measurement of what constitutes a chronic condition differ as well. They contend that a child’s developmental vulnerability; dependence on adult caregivers; and the different types, prevalence and patterns of chronic disease are indicative not only of different patterns of risk but also of the need for more sensitive and developmentally attuned health care system. (p. 166)

Children are not simply miniature adults, and hence, the mechanisms of treatment of children with chronic illnesses must reflect their unique biology and psychosocial experiences (Halfon & Newacheck, 2010). Refinements of treatment protocols for children are age, development, and educational-specific. Specialized protocols are designed to meet the comprehension and other unique needs of children. Although clinicians and researchers
have done well at integrating the needs of chronically ill children into outpatient treatment protocols, meeting the constantly changing needs of children in inpatient settings remains challenging (Halfon & Newacheck, 2010).

Children identified with chronic illness represent a growing portion of the school-aged population, a trend that poses a challenge for the U.S. education system. According to the Center of Disease Control (CDC) (2008), at present roughly 20% of school-aged children in the United States have a chronic illness (Hamlet, Gergar, & Schaefer, 2011). According to Halfon & Newacheck (2010), the prevalence of children with chronic illnesses in the U.S. has more than doubled since the 1960s. This increase is due to the improved ability to identify children with illnesses, as well as the improved ability to keep individuals with illnesses alive through medical intervention (Shiu, 2001; Thies, 1999). Children with chronic illnesses are not restricted from participation in the schools due to provisions afforded by Individuals with Disabilities Education Act (IDEA) and Section 504 (Thies, 1999). Despite these provisions—which require schools to provide education to this population—schools face a number of challenges in meeting the needs of children with chronic illnesses.

Thies (1999) articulated several of the challenges faced by schools in meeting the needs of children with chronic illnesses. As noted above, the first challenge is the rapid increase in the number of children with chronic illnesses; in addition to SCD, other chronic illnesses in the schools include asthma, obesity, and diabetes. The second challenge is the difficulty associated with the proper identification of children with chronic illnesses. To provide adequate levels of support, schools must be aware of any illnesses, but parents are often reluctant to provide information about chronic illnesses like SCD, Human Immunodeficiency Virus (HIV), or even Attention Deficit/Hyperactivity Disorder (ADHD)
that may be stigmatizing for their child. At present, such information is often obtained during kindergarten enrollment, when parents are asked to fill out a packet of information that may or may not ask specific questions about all domains of a child’s health—all of which leads to a partial identification of chronic illness. The third challenge is the lack of established systems to meet the needs of children with chronic illnesses and the difficulty in developing systems that can meet the diverse needs required by various conditions. The areas to be addressed include a wide range of physical, emotional, and academic needs. The final challenge is providing the necessary logistical support to accommodate children with frequent absences for medical treatment. Providing academic interventions to children who frequently miss school can be impossible if the child is not physically present; it is difficult to schedule one-on-one support services or even determine if academic difficulty is the result of a learning difficulty or due to missing class instruction and assignments.

SCD is one of the many illnesses that illustrate health disparities between White Americans and Black Americans (Braun, 2002). Health disparities exist between racial or ethnic groups due to socioeconomic status (SES) factors such as income, insurance status, and lifestyle factors. Of the extant literature, the majority has focused on pediatric and adolescent outcomes. For example, little is known about the effectiveness of educational processes or the educational outcomes of adult patients with SCD as a function of mood, social support, or other relevant factors. The current study contributes significantly to this literature by incorporating adults within the sample population.

**Sickle Cell Disease**

Chronic illness among children has been the topic of academic and medical research for decades (Schatz et al., 2001); SCD is one of the chronic illnesses explored (Fowler,
Johnson, & Atkinson, 1985). SCD is the most common genetic disorder of the blood and represents a group of related disorders including sickle cell anemia and sickle cell trait (Edwards et al., 2005). SCD is a recessive disorder affecting more than 50,000 individuals in the United States (Steen, Xiong, Langston, & Helton, 2003). SCD is most commonly found in individuals of African descent followed by those who are from Mediterranean countries, the Caribbean, Central and South America, Arabia, and East India (Bonner, Gustafson, Schumacher, & Thomson, 1999). Individuals with SCD experience a sickling of red blood cells that result in potentially occlusive masses of cells that are sticky, stiff, and deoxygenated. The abnormal attributes of such blood cells contribute to the frequent obstruction of blood vessels (Edwards, 2005). Tissue damage, delayed sexual maturation, pain, stroke, and pulmonary dysfunction are among the common symptoms of individuals who suffer from SCD (Jenerette & Murdaugh, 2008).

In addition to the physical and medical concerns associated with SCD, nervous and cognitive impairment can significantly influence interpersonal, social, intellectual, and educational functioning. The brain of an individual with SCD is affected by hypoxia and elevated toxins from degraded peripheral tissues just as much as the other bodily organs. Individuals with SCD commonly experience neurocognitive impacts that range from hypoxia and mild strokes to life-threatening acute bleeds and organ failures (Edwards et al., 2007). Edwards et al. (2007) found that central nervous system (CNS) complications are common and socially, intellectually, and educationally consequential among children and adults who suffer from SCD. The most common complication of SCD with cognitive sequelae includes transient ischemic attacks, seizures, increased cranial pressure, and silent infarcts. The neurological impact of SCD has only recently been acknowledged as a major consideration
for treatment while the neurocognitive and psychosocial impacts of SCD remain novel in the literature and few researchers in the United States work with adult populations.

**Sickle Cell Disease in Childhood**

Studies addressing school-aged children and the cognitive impacts of SCD have yielded varying results, and changes in the understanding of the neurological effects of SCD have resulted in the overturning of earlier research. Goonan, Goonan, Brown, Buchanan, and Eckman (1993) found that children with SCD did not differ from siblings without SCD in terms of cognitive functioning. Significantly, the study by Goonan et al. (1993) excluded any children who may have had neurological deficits and the results, therefore, may not have accurately represented the SCD population. Steen et al. (2005) found that children with SCD did, in fact, achieve lower scores on measures of cognitive ability compared to peers. The findings of Steen et al. (2005) therefore seem to indicate that the cognitive functioning of children with SCD may be lower than Goonan et al. (1993) concluded.

Even among children accurately diagnosed with SCD, the neurological effects of the disorder are difficult to measure. Hines, McKnight, Seto, and Kwiatkowski (2011) concluded that children with SCD experience neurological impacts more often than children without SCD, and children with SCD who are admitted to hospitals for headaches exhibit neurological damage more frequently than children without SCD (Hines et al., 2011). Children with SCD who experience headaches are also more likely to exhibit sustained neurological traumas than children with SCD who do not experience headaches. Frequent headaches are therefore believed to serve as markers for underlying neurological impairments or traumas. Still, not all children with neurological damage have a medical history of neurological damage, and not all forms of neurological damage are easily detected.
in the field without specific medical testing for such damage. The result is that even children with neurological damage may not be identified as having neurological damage.

One especially difficult form of neurological damage to detect is the silent infarct (Miller et al., 2001). A silent infarct is detected by Magnetic Resonance Imaging (MRI) and displays the same level of damage as a stroke, but individuals with silent infarct are unaware that they have suffered a stroke. Often the only symptom detectable by the individual sustaining a silent infarct is the presence of a headache. Silent infarcts frequently happen within the SCD population. Children who had suffered silent infarcts experienced more challenges in grade retention and required additional academic services (Schatz et al., 2001). Schatz et al. (2001) found that children with silent infarcts performed lower on cognitive tasks associated with attention and executive functioning than children who had not experienced silent infarcts. The lower levels of performance should come as no surprise as the children suffered substantial neurological injury; however, due to the difficulty in detecting an injury of this type, accommodations for children with silent infarcts are rarely made.

The neurological damage experienced by children with SCD can manifest in a wide variety of ways and can create a diverse set of educational challenges. Attention and executive functioning skills are important components of being successful in the academic setting. Deficits in attention and executive functioning may contribute to the high number of children with SCD experiencing grade retention (Schatz et al., 2001). The lower levels of attention and executive functioning in turn impact a child’s ability to attend to important materials, thus decreasing ability to encode information. Impairments in executive functioning impact a child’s ability to manipulate information that has previously been encoded to produce accurate information. The lowered levels of attention and executive
functioning, therefore, have a multiplicative impact on a child’s ability to perform at expected levels. Fowler et al. (1988) found that children with SCD scored lower on measures of reading, spelling, visual-motor skills, and attention than children without SCD. The findings of Fowler et al. (1988) are consistent with the findings of Schatz et al. (2001). In a later study, Schatz and Roberts (2005) found that children with SCD have difficulty with working memory compared to healthy peers, and these deficits in working memory may lead to an educational classification of learning disorder (LD) for children with SCD. Schatz and McClellan (2006) compiled the works of many researchers and determined that SCD should be viewed as a developmental disability due to the difficulties experienced in attention, executive functioning, reading, visual-motor skills, memory, and a high instance of LD classification. According to Schatz and McClellan (2006), children with SCD experience substantial impairments in cognition in addition to the many other areas of development in which SCD plays a detrimental role.

The academic struggles of SCD patients have been linked to language difficulties. Language is an important component of education and daily life and is needed to effectively communicate with others, including healthcare professionals. Language deficits in children with SCD have been observed in children as young as five to six years of age, and these deficits can impact the acquisition of more advanced language skills (Schatz, Puffer, Sanchez, Stancil, & Roberts, 2009). Findings by Tarazi, Grant, Ely, and Barakat (2007) indicate that children with SCD who attend school regularly have higher language skills, and therefore, they emphasize the importance of regular school attendance starting at a young age. As children with SCD typically miss more school than their healthy peers, improving access to education must be a priority.
The available research makes it clear that SCD impacts the academic experience of children in a wide variety of ways. Successfully identifying children who have SCD is an ideal first step towards improving educational outcomes for these children. There is at present no single recommended program for children with SCD, beyond emphasizing their unique developmental needs, providing any necessary academic accommodations for related LDs, and carefully monitoring them for possible silent infarcts. More specific academic interventions for this population have not yet been identified in the relevant literature.

**Other areas of impact in childhood due to sickle cell disease.** Cognitive impairments are not the only academic challenge faced by children with SCD. Absenteeism in particular—due to a variety of medical symptoms and medical appointments—tends to impede educational progress. SCD influences the regular sleep schedule of children, and this interruption in sleep in turn contributes to the high rate of absenteeism demonstrated by students affected with the disorder (Moskowitz et al., 2007). Children who are unable to sleep through the night because of their symptoms are often unable to rouse themselves and attend school; for these children, lack of attendance is one of the largest barriers to better academic performance (Schatz et al., 2001). Chronic pain presents another barrier to academic engagement. Pain crises are a common occurrence within the SCD population as a result of vaso-occlusion, the blockage of blood vessels by misshapen cells. When the flow of blood is blocked, oxygen is unable to circulate, and tissues can begin to die; this situation can be very painful. Areas commonly affected by pain crises include any region with capillaries, the smallest of blood vessels. Common sites for pain due to vaso-occlusion include the abdominal cavity (due to organ failure), the skin surface, and the lungs. Impairments in vision can result as well due to vaso-occlusion. Individuals with SCD, who experience such
pain crises tend to demonstrate higher rates of absenteeism, and those who do attend school show impairments in academic performance. In one study, children with SCD were found to miss an average of 21% of total school days, with half of the absences accounted for by chronic pain (Shapiro et al., 1995). Dampier et al. (2010) used a variety of performance metrics to review the impact of pain on children’s ability to function and concluded that SCD-related pain had a negative impact on academic performance.

Pain and fear of pain negatively affects students’ attention (Eccleston & Crombez, 1999). According to Eccleston and Crombez, pain and the fear of pain will supersede any other demands upon a child’s attention, regardless of the other environmental variables. Thus even with an elevated level of encouragement to participate in the academic setting, children who experience SCD-related pain will find it difficult to focus their attention and to match the classroom performance of their healthy peers. Furthermore, because even the fear of pain may be more demanding of attention than their immediate environment, children with SCD who do not actively experience pain in the classroom may still be distracted by the possibility of impending pain. Eccleston (2006) concluded that, for these children, “pain is an inescapable fact of life: pain will emerge over other demands for attention” (p. 363). The relationships among the experience of pain, the fear of pain, and attention in academic settings may ultimately have to do with the way that children process and cope with pain. Gil, Abrams, Phillips, and Keefe (1989) found that individuals with SCD tend to experience fewer pain crises as they enter adulthood and concluded that children and young adults may be less effective at coping with SCD complications than adults. A study conducted by Ross and Ross (1984) found that children rarely initiate pain coping techniques without prompting by others. Ross and Ross (1984) also indicated that children are rarely taught about pain in
schools and often do not receive anticipatory guidance for upcoming painful events, thus making it even more challenging to cope with the experience of pain. Vervoort, Goubert, Eccleston, Bijttebier, and Crombez (2006) found that children who do not utilize coping techniques are more likely to catastrophize their experience and suffer from negative effects, even when pain levels are relatively low. The findings of Vervoort et al. (2006), therefore, suggest that children are more likely to experience and report higher pain levels than adults due to the disparity in coping mechanisms rather than a significant difference in the pain itself.

A variety of psychosocial factors affect children with SCD in academic settings. Schatz and McClellan (2006) reported, for instance, that children with SCD are more likely to suffer from behavioral problems, social and emotional maladjustment, depression, poor self-image, and lower levels of popularity among peers than healthy students. Behavioral problems, specifically, may be directly related to academic difficulties and associated brain pathology (Edwards et al., 2007). Children with SCD tend to develop sex characteristics later than peers and are also observed to be smaller in stature due to problems with blood flow and poor oxygenation; these aesthetic differences tend to engender a feeling of self-consciousness among both male and female students. Priapism, or the persistent erection of the penis due to blocked blood flow, is often reported as an extremely embarrassing condition for boys and men of all ages and may lead to being taunted by peers. Frequent healthcare visits, the experience of pain, and limited social contact due to frequent absence increase likelihood of depression among the SCD population. All of these factors have been shown to contribute to lower rates of high school graduation. Swanson, Grosse, and Kulkami (2011) have defined the impact of SCD within the domain of the International Classification of Function,
Disability, and Health (ICF) and have shown that psychosocial limitations do not end in childhood. In particular, medical complications associated with multiple organ failure limit the participation of adults with SCD in community life. The adult experience of SCD is explored in further detail in a later section.

Hamlet, Gergar, and Schaefer (2011) found that children with chronic illness experience academic, social, and emotional challenges during their school years. To meet the academic demands placed on them, children with chronic illness require additional advocacy, as well as academic and psychosocial support. Children with SCD experience deficits in memory, attention, and motor speed; other challenges include increased absences, falling behind in schoolwork, negative feelings towards school, depression, anxiety, social withdrawal, and behavioral problems (Kaffenberger, 2006). Children with chronic illnesses who identify as “other health impaired” report significant academic challenges (Thies, 1999). Self-reported challenges include falling behind in schoolwork, academic retention, and a fear of being unemployed after completing school. Despite these difficulties, less than 10% of children with chronic illness have individualized educational plans (IEPs); this situation may be because children with chronic illness appear to function well enough to maintain their academic performance and do not seem to require academic intervention.

One challenge for healthcare and educational advocates is that the academic performance of children with chronic illness tends to fall somewhere between healthy students and students classified as exceptional. As a result, even when they do not perform at a level commensurate with their peers, they are rarely considered candidates for additional academic support or for the referral to special education teams. Further, children with chronic illness may be high functioning until they experience a crisis.
students need additional supports like tutoring, supplemental instruction, extensions of deadlines, or copies of missed notes. In such a scenario, children who experience only subtle academic challenges may be at a disadvantage compared to children who are at strong risk of academic failure, because the latter will more likely be afforded additional means of support. Educators may fail to identify children who experience only subtle or sporadic academic challenges as requiring extra supports (Shiu, 2001).

Individuals with SCD are less likely to complete high school than their healthy peers and face a wide variety of challenges over the course of their academic careers (Barbarin, Whitten, & Bonds, 1994). According to ICF, children with SCD commonly experience impairments in communication, perception, academics, mobility, self-care, recreation, and personal relationships (Swanson et al., 2011). A 2006 study observed a significant decrease in productivity among children with SCD (Todd et al., 2006). The decrease in productivity was manifested as slower speed of task completion, fewer tasks completed, and irregular school attendance. Pain crises that prevent school attendance occur at least once per year in 60% of children with SCD and at least once per month for 20% of these children. The combined impact of these variables—cognitive impairment, decreased productivity, and frequency of absences—means that children with SCD are more likely to be categorized as suffering from a learning or developmental disorder, and children with LDs are more likely to drop out than children without LDs (Dunn, Chambers, & Rabren, 2004). LDs may not be the only contributing factor to the higher dropout rates among the SCD population; Schatz and McClellan (2006) have argued that it is the psychosocial impacts of SCD that account for the higher dropout rates. For example, children with SCD tend to exhibit lower levels of popularity, lower self-esteem, and delayed sexual maturation—all of which potentially
contribute to an experience of social isolation or depression, and all of which may serve as deterrence to regular school attendance or as motivation to dropout.

The consequences of failing to complete high school are severe. Individuals who do not complete high school experience severe social and economic challenges compared to those who do graduate. According to Dunn et al. (2004), individuals who drop out of high school tend to earn less money, have lower self-esteem, and face greater social risk, all of which correlate with lower QOL measures. The impact of educational attainment on health has also been documented: higher educational achievement is known to predict better health outcomes later in life (Ross & Wu, 1996; Cutler & Lleras-Muney, 2006). Higher educational attainment may also support improved functioning in advanced age while a lack of education may impede later life functioning (Johnson, Deary, McGue, & Christensen, 2009). According to Ross and Wu (1996), individuals with higher levels of academic achievement have better health than those with lower levels of educational attainment; moreover, the longer an individual lives, the higher the discrepancy. Ross and Wu’s findings are supported by those of Lynch (2003), who examined education and health to determine if cohort effects could account for the disparity. Lynch (2003) found that the impact of education on health does, in fact, increase as a function of age and cannot be solely attributable to cohort effects. A failure to obtain a high school diploma is correlated with an increased likelihood of disability and lower levels of health-related QOL (Latham, 2012; Knight et al., 2007).

Long-term health outcomes are not the only variable affected by educational attainment. Educational attainment has been shown to correlate with increased cognitive functioning, a desire to pursue healthy behaviors, and an improved ability to respond to trauma (Ford, 2012; Pai & Tsai, 2005; Cutler & Lleras-Muney, 2010). Cutler and Lleras-
Muney (2006) found that individuals who have earned a high school diploma are expected to live an average of 54 years after graduating high school, while individuals who failed to graduate high school are expected to live for only 46 additional years. Cutler and Lleras-Muney found that life expectancy is also related to behavioral factors deriving from educational experiences. Individuals with high school educations have better health behaviors than their counterparts who do not; for example, those without high school degrees are more likely to smoke cigarettes. High school completion is correlated with lower death rates as well and is more important in predicting health for individuals who are Black than for those who are White, regardless of income (Freudenberg & Ruglis, 2007). Freudenberg’s findings are of special significance to this study, as SCD is found predominantly within the Black community. As individuals who are Black are already more likely than their White counterparts to demonstrate poor health outcomes, it is of utmost importance to encourage a high level of educational attainment within this demographic so they can experience the health benefits associated with higher educational levels.

In addition to an individual’s educational attainment, maternal educational attainment can impact later life outcomes. More specifically, maternal educational level can affect not only the mothers’ approaches to parenting and to discipline, but also the birth weight and eventual health outcomes of their children (Kleinman & Madans, 1985; Gakidou, Cowling, Lozano, & Murray, 2010; Fox & Platz, 1995). These findings suggest that mothers with a higher level of educational attainment tend to raise children who in turn achieve better life outcomes. Significantly, Gakidou et al. (2010) found that the global increase in educational attainment among women of reproductive age has resulted in over eight million fewer deaths in the span of three decades. A study by Gakidou et al. (2010) suggests that the children of
mothers with higher educational attainment are more likely to live longer and conversely that the children of mothers with lower educational attainment are more likely to suffer from childhood mortality.

Maternal education continues to affect children throughout childhood. For example, mothers with less than 12 years of formal education are more likely to deliver children with lower birth weight. Birth weight is a strong indicator for other childhood health variables (Kleinman & Madans, 1985). Kleinman and Madans (1985) demonstrated that correlations exist between higher birth weight and outcome variables like better overall health, a lower instance of LDs, and higher academic achievement. Lower birth weights, by contrast, have been linked to lower levels of high school graduation and difficulties in obtaining employment. Low birth weight has immediate and apparent impacts, but outcome variables like academic achievement and the manifestation of LDs may continue to have ramifications for many years.

Educational attainment also affects the parenting behaviors of mothers. For example, maternal educational level can moderate the effects of low SES and discipline practices (Fox, 1995). According to Fox (1995), mothers with low SES and low educational attainment tend to use undesirable discipline practices, while mothers with low SES and high educational attainment used more desirable disciplinary methods.

**Education about sickle cell disease.** Patients with SCD are rarely adequately educated about specific conditions that may result from SCD or mechanisms for management. This shortcoming is significant because educating patients about the mechanisms of SCD has been shown to improve disease prognosis and clinical outcomes (Jenerette & Murdaugh, 2008). Education about self-care techniques, disease prevention, and
medical adherence has likewise been associated with improved health status among individuals with SCD. Despite evidence that education about SCD improves health status, there is a general lack of knowledge about the disorder between both children with SCD and their parents. Although there are a growing number of psychological interventions designed to facilitate management of symptoms and coping, few providers or parents seem aware of the options available to them (Edwards & Edwards, 2010). Better educational outreach would help patients familiarize themselves with possible complications and help ensure that they seek appropriate treatment if or when such conditions arise.

Parents of children with SCD are often inadequately educated about their child’s disorder, and their lack of education can inhibit access to appropriate medical treatment (Logan, Radcliffe, & Smith-Whitley, 2001). Logan et al. (2001) found that parents who scored lower on quizzes measuring basic familiarity with SCD attended routine medical appointments less frequently than parents who demonstrated higher levels of basic knowledge. In another study, children and caregivers of children with SCD were interviewed in order to assess their knowledge of the increased risk or warning signs of stroke (Katz, Smith-Whitley, Ruzek, & Ohene-Frempong, 2002). Only one third of caregivers and one tenth of children were able to identify stroke as a possible health concern associated with SCD. Stroke is a major health concern for SCD and may lead to impairments in all areas of life, including cognitive and academic functioning. Due to the low level of education regarding stroke among caregivers, and the even lower awareness among children, it is evident that schools and educators are also inadequately informed about the risks of stroke. Stroke has a rapid onset and serious consequences, often leading to the loss of life or permanent brain damage. Early response to stroke may decrease the magnitude of the long-
lasting effects of stroke and brain damage may be mitigated with early treatment. Together, the necessity of an early response for successful treatment and the lack of knowledge about the symptoms of stroke indicate a need for increased education within the SCD population.

Parents of children with SCD report concerns about their child’s memory and academic abilities despite the progress being made in the methodology of treatment of SCD (Dyson, Atkin, Culley, Dyson, & Evans, 2011; Peterson, 2005). Wills et al. (2010) found that youth with SCD, and their parents, were amenable to the use of neurocognitive measures during routine visits; furthermore, the researchers found that parents correctly identified the presence of any neuropsychological deficits and believed that their children’s needs were not being addressed by their schools. Children with SCD can exhibit brain injury in the form of a stroke or a silent infarct; neuroimaging can be useful in identifying neurocognitive deficits in children with SCD who otherwise demonstrate no other indication of brain injury (Bonner et al., 1999).

A possible explanation for the lack of knowledge among the SCD community may be a comparable lack of awareness within the medical community. A lack of knowledge among medical professionals interferes with patients’ access to appropriate medications, care, and often leads to exacerbation of symptoms (Haywood et al., 2009). Studies have demonstrated that healthcare professionals often misinterpret symptomatology of SCD patients and assume legitimate pain crises are signs of drug-seeking behavior associated with substance abuse (Elander, Marczewska, Amos, Thomas, & Tangayi, 2006). Since the early 1990s, screening at birth has been commonplace (Chaine et al., 2001); however, as the disorder is not well understood even within the medical profession, parents are often left uneducated about the disease and its impacts when the disease is identified at birth.
Educational interventions have been shown to have positive impacts on children’s educational development, both directly and indirectly. Three types of educational interventions—with the child, with the community/family, and with professional healthcare providers—have all been found effective in different ways.

Interventions for improving management of pain have been effective for children with SCD. Pain is a common reason for children with SCD to miss school, but teaching children cognitive techniques for managing pain from SCD positively impacted their experience of pain (Gil et al., 1996). A child’s coping style has also been shown to affect their relative resilience to SCD (Ziadni, Patterson, Pulgaron, Robinson, & Barakat, 2011). Cognitive techniques for pain and stress management can be taught in the school setting through a school counselor or school psychologist. Daly, Kral, and Brown (2008) addressed the need of school psychologists to become involved in the treatment of children with SCD and articulated some appropriate ways for school psychologists to advocate for children in their schools. There have been no studies found within the available literature directly addressing the efficacy of interventions among SCD students in an academic setting, and there have been no outcome studies of adults with SCD to determine whether educational outcomes correlate with symptom severity later in life.

Educational interventions aimed at the community have also been effective. Community-based educational programming has been shown to improve the treatment of children with SCD. Successful community-based interventions included manualized family psychoeducational intervention, online peer educational systems, community-based education initiatives, and instruction in self-advocacy skills (Butler & Beltran, 1993; Hazzard, Celani, Collins, & Markov, 2002; Kaslow et al., 2002; Rouse, 2011). Schools are an
ideal location for such programming and allow individuals to interact with others involved in the life of children with SCD.

Effective interventions have been identified for professional healthcare providers who work with children with SCD. Educating physicians about cultural competence or transitional planning has improved treatment outcomes (Kaslow et al., 1995; Rouse, 2011; Thomas & Cohn, 2006). Education among healthcare professionals within the school system could easily be conducted on a one-time basis and regularly reviewed as part of continuing education requirements.

**Sickle Cell Disease in Adulthood**

Challenges related to SCD affect individuals throughout their lives. Those born prior to the 1980s may not even be aware of their disease status since fetal screening within the United States was not a widespread practice until more recently. Fetal screening has improved the life expectancy of individuals with SCD, but the cost of disease treatment remains high (Chaine et al., 2001). Studies from 1973 indicate that the life expectancy of a child with SCD was only 14 years; today, with the incorporation of screening for SCD at birth and improved interventions, the average lifespan of patients with SCD is approximately 48 years (Figueiredo, 2013), or more than three times as long as in the past. In addition to screening and medication management, a number of other factors have promoted a longer lifespan among individuals with SCD. A study conducted by Platt (1994) indicated that individuals who died earlier than their peers with SCD died most often during an acute pain crisis, chest syndrome, or stroke. These findings demonstrate the importance of adequate preparation and quick response to such events. Prevention of incidents like these is vital to promote the quality and the duration of life with SCD. Other factors contributing to improved
life expectancy include psychological intervention, pain management strategies, and better education. According to Edwards et al. (2005), effective management of SCD requires preventative medical care, treatment for pain crises, patient education, cognitive behavioral therapy (CBT), and psychosocial therapies. Patient education serves to inform individuals with SCD about their disease, its symptoms, and the best methodologies for avoiding and treating complications. CBT helps individuals with SCD better manage their disease by finding adaptive methods to cope with the illness rather than relying on unhealthy and counterproductive coping styles. Psychosocial interventions have had significant impacts on the presentation of symptoms, as individuals with poor psychosocial functioning tend to suffer from more severe SCD-related problems. By directly addressing the psychological and educational aspects of SCD QOL and life expectancy can be improved. Psychological interventions have been cost effective at decreasing symptom severity and frequency of pain crises.

Medication has been effective at improving the life expectancy of an individual with SCD but can be costly. In addition to the cost of medications for maintaining an appropriate level of day-to-day health, other medical treatments—including costly and invasive treatments like transfusions and bone marrow transplants—are often required. The result is that individuals with SCD are frequently subjected to financial hardships. According to Kauf (2009), individuals with SCD spent an average of approximately $1,500 per month to manage their disease, and the cost of medical management increases with age. The majority of healthcare costs came from inpatient hospitalizations directly related to SCD, though interestingly, within the SCD population in the study, the non-SCD-related costs of health care were also higher than the national average for the general population. These findings
indicate that individuals with SCD may experience additional burdens on their health that are not directly SCD-related but that the typical American may not experience.

Patients with SCD are often skeptical of medical treatments (Fiscella, Franks, & Clancy, 1998). Fiscella et al. (1998) found that skepticism regarding treatments and medical professionals may contribute to low levels of medical adherence, whether through inconsistent attendance at appointments or through a failure to take medications as prescribed. Still, despite widespread skepticism, medical advances have made the management and treatment of SCD more effective, and individuals with SCD today are living longer and encountering a new set of challenges associated with aging (Platt, 1994).

QOL can be defined in a number of ways and measured with a variety of differing metrics. In general, QOL metrics seek to encompass several domains of a patient’s life and to allow medical professionals to accurately quantify the domains. It is important to address QOL within the SCD population due to the increased life expectancy within the SCD population (Figueiredo, 2013). McClish (2005) assessed the QOL of individuals participating in the Pain in Sickle Cell Epidemiology Study in areas of physical function, physical and emotional role function, bodily pain, vitality, social function, mental health, and general health. McClish found that the SCD population experienced poorer health-related QOL than the general population; SCD patients reported lower QOL than individuals with other forms of chronic health conditions. In particular, individuals with SCD demonstrated less favorable scores than the average population in measures of bodily pain, social function, and mental health; each of these variables is considered below in greater detail.

**Bodily pain.** Bodily pain significantly impacts QOL among individuals with SCD, who are prone to experience two different modalities of pain: chronic pain and pain crises (Edwards
et al., 2005). Pain crises are commonly defined as acutely painful sickling-related episodes lasting more than four hours that require medical attention (Charache et al., 1995). As mentioned earlier, pain crises can occur rapidly with no warning of onset. Pain crises consist of intense bouts of pain. Pain crises often result in individuals seeking immediate care in facilities such as doctors’ offices or emergency departments. Pain crises are best treated with early intervention and, due to the severity of pain, are usually not improved with the use of low-strength medications. Because high-strength pain medications are required, the hospital emergency department is often the first treatment choice for many patients with SCD; however, due to frequent attendance at emergency departments, individuals with SCD are often misidentified as exhibiting substance-abuse-related drug-seeking behavior and may be refused necessary treatment.

For SCD patients, pain presents itself in a wide variety of manifestations. Ballas (2005) has theorized five principal types of pain: acute pain syndromes, chronic pain syndromes, neuropathic pain, pain secondary to therapy, and pain due to comorbidities. Acute pain syndromes are recurrent and include the pain crises described above; pain crises may be due to factors such as acute chest syndrome, hepatic crises, or priapism. Chronic pain may have objective signs due to conditions like avascular necrosis leg ulcers or chronic osteomyelitis; chronic pain can also manifest without objective signs simply as an intractable chronic pain. Neuropathic pain may be secondary to therapy or medical intervention. Neuropathic pain, secondary to therapy, may include incidental pain due to treatment like withdrawal, prosthesis-related pain, or postoperative pain. Finally, pain may be due to comorbid conditions including pain resulting from trauma or chronic conditions like arthritis. Individuals may suffer from chronic pain for several years or longer.
Chronic pain has been shown to have negative implications for physical health, daily activity, psychological health, employment, economic wellbeing, depression, sleep disturbance, fatigue, and decreased overall physical functioning (Smith et al., 2001; Woolf & Mannion, 1999; Feine & Lund, 1997). According to Smith et al. (2001), “‘significant’ and ‘severe’ chronic pain . . . is associated with even poorer indicators of health and disability” (p. 298). Findings of Smith et al. suggest that the more severe an individual’s experience of pain, the more severe the impact on health and disability. Ballas et al. (2006) collected data on individuals with SCD using hydroxyurea—a common medication for SCD management—to determine how hydroxyurea affected QOL measures. They found that “compared with patients with other chronic conditions, patients with SCD had lower (worse) scores than all other groups in the domains of physical role functioning, social functioning, health perception, and body pain” (p. 298) but that patients who reported taking hydroxyurea did experience less impairment in all domains.

**Social function.** Psychosocial functioning is often negatively impacted among adults with SCD, both by specific psychiatric disorders as well as by general limitations in healthy psychosocial functioning (Asnani, Frazer, Lewis, & Reid, 2010; Ballas, 2006). In particular, individuals with SCD are prone to high rates of psychosocial complications that manifest as psychological distress, and many suffer from depression and anxiety (Asnani, 2010). Moreover, Ballas et al. (2006) found that patients using hydroxyurea experienced significant QOL limitations in the domain of social functioning. A study by Thomas and Taylor (2002) involved interviewing individuals with SCD to understand the specific psychosocial impacts of SCD. In that study, the researchers concluded that SCD “undermines quality of life in important ways” specifically related to psychosocial functioning. Interviewees identified
problematic areas in both physical and psychological functioning, including poor socialization, fewer occupational choices, greater obstacles to formal education, and negative effects on relationships.

SCD has been shown to have negative effects on relationships (Thomas & Taylor, 2002), while greater levels of social support had positive effects on those with SCD (Edwards et al., 2005). In general, chronic health conditions can take a heavy toll on interpersonal relationships (Midence, Fuggle, & Davies, 2011), and individuals with SCD, in particular, have been found to experience difficulties in both social and familial relationships (Edwards et al., 2005). Chronic pain, financial difficulties due to lack of employment, cost of medical treatment, and communication difficulties resulting from medications, pain, or cognitive impairment can strain relationships between individuals with SCD and those around them. Psychosocial strain has been correlated with perceived lower levels of social support and increased depressive symptoms. Though individuals who report high levels of social support also report better psychological adjustment (Midence et al., 2011; Robert, Gil, Abrams, & Phillips, 1992), social support is often lacking within the SCD population. Midence et al. (2011) found that family relationships often do not offer support to individuals suffering from SCD and suggested that this phenomenon may be related to the fact that SCD is an inherited disease. In other words, because individuals with SCD often have siblings or parents with SCD, physical and emotional resources tend to be available only in limited supply. SCD-related limitations on physical and emotional resources increase stressors in the home and decrease a family’s ability to provide support for one another.

Because the presence of adequate and diverse social support tends to correlate with strong individual coping skills and psychological adjustment, evaluating an individual’s level
of social support can provide an indirect measure of their psychosocial functioning. According to a literature review compiled by Gallant (2003), there is “evidence for a modest positive relationship between social support and chronic illness self-management” (p. 170). Data from Gallant suggests that social support improves the QOL and the ability to manage illness.

The health of individuals with SCD is effected most by the presence and degree of support from an intimate relationship. Collins and Feeney (2000) found that individuals in better-functioning relationships were able to provide more supportive interactions to their partners. The perceived support that an individual receives in a relationship increases as a function of the relationship. In a related study, Horner (2001) addressed the impact on overall health of the perceived level of support within a relationship, and found that increased support translated to better health. While positive support has been shown to promote health, low levels of intimate support have been shown to contribute to future illnesses. Finally, a partner’s response to healthcare needs can impact the level of satisfaction within a relationship: Rafaeli and Gleason (2009) concluded that “individuals who feel that their partner responds to their needs will be happier and in a healthier relationship” (p. 32).

A review of SCD-specific literature returned no studies addressing the impact of social support and disease severity. Given that social support is related to QOL in individuals with chronic illness, as indicated by Gallant (2003), further investigation of supports may be insightful in understanding QOL and disease severity. As stated above, individuals with SCD are more likely to experience difficulties in social settings due to developmental delay related to SCD (Schatz and McClellan, 2006). Further investigation regarding social to support may increase understanding of the needs of the SCD population.
**Mental health.** Depression is often comorbid with chronic illnesses (Moussavi et al., 2007), and is frequently found among individuals with chronic pain. Banks and Kerns (1996) conducted a review of literature and found that in studies regarding pain and prevalence of depression, prevalence may be as low as 10% or as high as 100% in certain populations. The link between depression and SCD has been the topic of recent research, and individuals with SCD were found to exhibit higher frequencies of depression than the Black American population at large (Hasan et al., 2003). Within the SCD population, factors detrimental to QOL like the experience of chronic pain can contribute to depression: higher rates of depression have been found among SCD patients with high instances of painful episodes, a correlation that implies a direct relationship between disease severity and the experience of depression (Schaeffer et al., 1999).

**Socioeconomic influences.** SES has been correlated with health outcomes: individuals with high SES are likely to have better health outcomes than individuals with low SES (Ellison & Bauchner, 2007). The correlation between SES and health outcomes also holds true in the SCD population. An example of this is the length of hospital stay following a vaso-occlusive event. Individuals with low SES, as measured by access to medical insurance, experience longer hospitalization compared to individuals with higher SES. SES in SCD individuals differs from the overall U.S. population as well as the Black population in the United States on a number of factors beyond health-related factors. In a large-scale study conducted between 1979 and 1981, Farber (1985) found that individuals with SCD experience household differences when compared to healthy peers. Individuals with SCD are more likely to have single-parent families, single female heads-of-household, individuals that were disabled, lower incomes, and lower high school graduation rates than individuals
without SCD. Likewise, Palermo, Riley, and Mitchell (2008) found that family socioeconomic conditions predicted physical health-related QOL, psychosocial QOL, and reported functional disability in children. Parental education was related to physical and psychosocial QOL.

**Gender differences.** Gender differences within the SCD population have been researched for several years. Steinberg et al. (1995) found that gender and haplotype, based on heritable deoxyribonucleic acid (DNA) variation, influenced adult expression of SCD in 384 participants. Findings suggest that the adult experience of SCD is dependent not only on the DNA of an individual but also their gender. Specifically Steinberg et al. (1995) found that the level of fetal hemoglobin (HbF) in blood varied with gender, and higher HbF levels are linked to milder symptoms of SCD (Akinsheye et al., 2011). Gender has also been linked to other aspects of SCD.

Gender differences in expression of SCD have been observed in life expectancy. In a study of over 3,900 adults with SCD, Platt (1999) found that women with SCD live longer than men. These findings are consistent with Pegelow et al. (1997) who found that similar blood pressures can result in different mortality rates for men and women. In a study of over 3,300 individuals with SCD, Pegelow (1997) found that men were at higher risk for death than women with similar blood pressures supporting the notion that men and women experience differences in impact of disease.

Experience of pain within SCD may also vary with gender. McClish (2006) found that men and women experience different lengths of pain crises. Men remain in pain crises for longer lengths of time than women; men also utilize medical services more often than
females. The findings suggest that men may experience pain more intensely than women with SCD.

Gender differences have been observed in levels of incomes. Farber (1985) found that males with SCD had lower incomes than healthy Black males. He also found that females with SCD were likely to have the same salary as healthy Black females. The differences in gender within SCD are not only observable within adults.

Differences in SCD based on gender can be detected during childhood in caloric intake as well as body mass index (BMI). A study of 133 children with SCD found that males were further behind expected growth curves than females (Phebus, Gloninger, & Maciak, 1984). These findings were similar to Modebe and Ifenu (1993) who found that men with SCD were likely to have BMI measures that were significantly lower than men without SCD whereas women with SCD had BMI measures similar to healthy women. Also of note is that men with SCD ate fewer calories per day than healthy peers while women with SCD again resembled healthy peers. The results of Modebe and Ifenu (1993) were based on a sample of 20 adults with SCD and may not accurately represent the entire SCD population.

**Severity.** As with any disease, individuals with SCD have varying disease severity. There are many factors that may influence the severity of SCD. One factor is the type of SCD an individual may have. Within SCD, there are many subtypes, and severity of disease varies based on subtype. The type of SCD depends on the genes inherited from the individual’s parents. The three most prevalent types of SCD are—from most common to least common—HbSS (SS), HbSC (SC), and HbSβ thalassemia (Sβ) (Hassell, 2009). According to the CDC (2014), SS is usually the most severe type of SCD and results from an individual inheriting an “S” gene from each parent. SC is usually considered a milder subtype and
results from inheriting one “S” and one “C” gene from parents. Within Sβ, there are two subtypes, “0” or “+”. The 0 subtype typically results in a severe type of SCD while the + is commonly more mild.

As indicated above, the subtype of SCD impacts the severity of symptoms associated with SCD. Individuals with SS or Sβ experience increased mortality (De Castro, Jonassaint, Graham, Ashley-Koch, & Telen, 2007). This increase is related, in part, to the increase in kidney and heart disease in individuals who have the most severe forms of SCD. Individuals with SS are more likely to suffer from hemorrhagic stroke with up to 50% of patients dying within two weeks of the stroke (Strouse, Hulbert, DeBaun, Jordan, & Casella, 2006). Individuals with the more severe forms of SCD (SS and Sβ) are more likely to maintain medical adherence in terms of attending medical appointments compared to the less severe forms, but still have lower rates of survival (Quinn, Rogers, McCavit, & Buchanan, 2010).

Resilience

Resilience theory posits that individuals can overcome adversity because of protective factors (VanBreda, 2001). Protective factors are positive influences that help an individual negotiate risks due to adversities. Protective factors may include access to tangible resources such as income and housing. Protective factors may also be intangible such as relationships or academic attainment.

Resilience in sickle cell disease. Resilience in SCD has been found to be linked to many protective factors. Protective factors within SCD include lower medical severity, psychosocial factors, socioeconomic variables, (Burlew, Telfair, Colangelo, & Wright, 1998; Devine, Brown, Lambert, Donegan, & Eckman, 1998; Logan, 2001). According to Devine (1998), parental socioeconomic factors were able to predict academic achievement and
intellectual abilities in children with SCD. Burlew (1998) found that psychosocial factors such as social assertion, self-esteem, use of social supports, and family relations accounted for a significant amount of variance in an individual’s ability to adapt to challenges related to SCD. Overall, psychosocial factors accounted for more variability in adaptation to SCD in a national sample than medical factors, and medical factors serve to predict different areas of adjustment to SCD in addition to psychosocial factors.

To date, little research has been conducted regarding the ability of education to serve as a protective factor in individuals with SCD. Research regarding education and SCD is based on patient education about medical matters. Studies regarding the importance of medical education of parents of children with SCD have been conducted for several decades. Leikin et al. (1989) stated that mortality rates of children decreased due to parental education, counseling about SCD, and the use of antibiotics. Education related to medical matters has improved medical adherence and decreased rates of mortality.

**Study Purpose and Rationale**

The relationship between educational attainment and later life outcomes has been a topic of research for many health and medical conditions, including cancer, general aging, genetics, heart disease, and epilepsy (Johnson et al., 2009; Knight et al., 2007; Latham, 2012; Pai & Tasia, 2005). In general, education is a protective factor and individuals who complete a K-12 education fare better than those who do not; individuals who continue to complete post-secondary education tend to have the best life outcomes. A review of published SCD-related literature, however, discovered no studies that evaluated the impact of childhood education on later life outcomes among individuals with SCD.
It is well documented that SCD is a risk factor and negatively impacts an individual’s educational attainment. Individuals with SCD are less likely to complete high school than individuals without SCD (Todd et al., 2006). In a study of the general public, Ross and Wu (1996) found educational attainment decreases reports of symptom severity later in life. Cutler and Lleras-Muney (2006) found results similar to those of Ross and Wu (1996) when reviewing publications regarding the positive impact of education on symptom severity. The relationship between educational attainment and disease severity indicates there may be an opportunity to develop a preventative framework for school psychologists to enact. National Association of School Psychologists (NASP) suggests the use of school personnel to bolster protective factors for children with chronic illnesses (McCabe & Sharf, 2007). What is not addressed in previous studies is whether academic challenges are linked to poorer outcomes in the SCD population in adulthood. Literature suggests a positive relationship between academic achievement and life outcomes within the general population, and if this relationship is observed within the SCD population it may guide the development of future preventive interventions for educators working with children who have SCD.

School psychologists generally become involved in the treatment of a child when their needs become evident due to difficulty in the classroom or after SCD-related medical crises such as ischemic attacks or stroke. Best practices among school psychologists, however, involve developing preventative interventions rather than responsive interventions, and so it is crucial that school psychologists are proactive in identifying and meeting the needs of the children with SCD in their schools.

Children with SCD, regardless of their stroke status, are at an increased risk of neurological difficulties (Noll et al., 2001), and school psychologists must be educated about
the course and treatment of the disease to prevent avoidable negative outcomes. Even children with SCD who have never reported a case of stroke are still at risk of stroke, and Schatz et al. (2001) found that children with SCD are more likely to experience impaired cognitive function, decreased memory, and decreased short-term memory. Moreover, the neuropsychological impacts of SCD increase as individuals increase in age (Vichinsky et al., 2010), and older individuals demonstrate poorer performance on Wechsler assessments than younger individuals. According to Daly et al. (2008), school psychologists should be involved in the academic monitoring of all children with SCD to better identify performance declines.

The best way for school psychologists to meet the needs of children with SCD is through advocacy, prevention, and support (Daly et al., 2008). Freudenberg and Ruglis (2007) encourage greater collaboration between healthcare providers, including school psychologists, to decrease dropout rates and address the needs of students, families, and the community at large.

The effects of SCD in the academic setting have been studied for a number of years (Schatz et al., 2001), and, as a result, much is known about the impact of SCD on academics. Based on previous research regarding SCD in schools, it is known that children with SCD encounter a number of challenges in the academic setting (Schatz & McClellan, 2006), and that these challenges lead to lower rates of school completion as well as poorer social adjustment compared to healthy peers. Also well documented are the difficulties encountered by adults who do not complete high school and those with social adjustment problems while in school (Freudenberg & Ruglis, 2007; Gallant, 2003). The links between disease severity and poor health outcomes for individuals with chronic illness have been addressed in various
studies. Individuals with lower levels of educational attainment typically experience more severe symptoms in chronic illness, and lower levels of social support. Further, social adjustment has been shown to correlate with higher disease severity. However, the relationship between educational attainment and later life outcomes within the SCD population has not been examined.

Additional research will allow for a better understanding of the relationship between educational attainment and later life outcomes. Research examining educational attainment should account for factors that have previously been identified as contributing to later life outcomes within the SCD population. One factor linked to the later life outcomes of SCD is an individual’s gender. Gender has been shown to impact biological factors such as blood composition (Chang, 1995), experiences of symptoms such as pain severity (Akinshey, 2011; McClish, 2006), overall life expectancy (Platt, 1994), and the effect of blood pressure on mortality (Pegelow, 1997). Gender was also related to income level (Farber), diet, and BMI in children (Phebus, 1984) within individuals with SCD. Gender has demonstrated an influence on the experience of SCD in several domains and may influence additional domains not yet explored. As such, gender will be included in the present study and will be explored in the analysis of educational attainment.

Disease severity has also been influential in the experience of SCD. Disease severity in SCD can be defined through disease type (CDC, 2014). Disease type has been found to impact life expectancy and incidence of stroke (De Castro, 2007; Strouse, 2006). Disease severity, based on disease classification, has also been used to determine the appropriate course of treatment for children at the time of birth for the first several years of life (Hirst, & Owusu-Ofori, 2014). Disease severity has been influential in life outcomes yet research on
chronic illness and educational attainment, in general, have regularly demonstrated that educational attainment may be more impactful than disease severity (Cutler & Lleras-Muney, 2006; Johnson, Deary, McGue, & Christensen, 2009; Lynch, 2003; Ross & Wu, 1996).

The aim of this study is to investigate the ability of gender, educational attainment, and disease severity to predict adult outcomes within the SCD population. A review of the literature found gender differences occur within several domains of SCD, that children with SCD experience academic difficulties, and SCD disease severity has been linked with later life outcomes. As yet, the ability of gender, childhood academic attainment, and disease severity to predict adult levels of depression, pain, relational support, income, and employment status, have not been examined within a targeted SCD population. The purpose of the proposed study is to gain further understanding of the ability of gender, educational attainment, and disease severity in predicting outcomes in adults with SCD.

**Research Questions**

Question 1: Does gender significantly predict the outcomes of pain, depression, relational support, income, and employment status in persons with Sickle Cell Disease?

Question 2: Does the addition of educational attainment to gender significantly predict the outcomes of pain, depression, relational support, income, and employment status in persons with Sickle Cell Disease?

Question 3: Does the addition of disease severity to gender and educational attainment significantly predict the outcomes of pain, depression, relational support, income, and employment status in persons with Sickle Cell Disease?
CHAPTER III: RESEARCH METHODS

Data Source

The present study draws on a cross-sectional survey evaluation of first-year data collected using the Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease (LEMPFSCD). The LEMPFSCD is a longitudinal evaluation of the relationship between medical and psychosocial factors and pain in adults with SCD (Pells et al., 2005). Data collection for the study began in 2001 as part of the Parental Substance Abuse, Chronic Pain, and Coping in Adult Patients with Sickle Cell Disease, a long-term study regarding alcohol use in parents of individuals with SCD. Participants in the proposed study were all at or above the age of 18 at the time of the initial data collection.

Participants

All participants were 18 years of age or older at the time of survey completion and completed the LEMPFSCD (Pells, 2005) as part of an ongoing study described below. Individuals excluded from data analysis included individuals who were unable to read the instructions, and as a result 254 participants remained for analysis.

Procedures

Pain, depression, satisfaction of level of support in relationships, income, and employment status in adults were explored as outcome variables based on endorsements of gender, educational attainment, and disease severity. Archival data from an ongoing study on Parental Substance Abuse, Chronic Pain, and Coping in Adult Patients with Sickle Cell
Disease (Edwards et al., 2006) being conducted at Duke University Medical Center was used to examine the research questions. Participant data was supplied from the ongoing study, Parental Substance Abuse, Chronic Pain, and Coping in Adult Patients with Sickle Cell Disease, using the LEMPFSCD instrument (Pells, 2005). Information specific to participant gender, education level, disease severity, pain level, satisfaction of support in relationships, depressive symptomatology, income, and employment status were examined for the purposes of the current study. The Duke University Medical Center’s Institutional Review Board (IRB) approved the archived study. The University of North Carolina at Chapel Hill IRB on 1/21/15 deemed that the current study did not require IRB approval (Study # 13-3704). The present study includes analysis of data from questionnaires given during baseline data collection of the archived study.

Measures

Longitudinal exploration of medical and psychosocial factors in sickle cell disease. The LEMPFSCD (Pells, 2005) is a multidimensional pencil-and-paper instrument designed specifically for the examination of the SCD population. The measure was administered to 256 participants during the first wave. The LEMPFSCD is a 700-question tool consisting of demographic information, pain assessment, and eight validated, content-driven instruments for the assessment of psychiatric, behavioral, and social functioning. Individual scales within the LEMPFSCD have had their reliability and validity assessed. Overall, the reliability of the LEMPFSCD has not yet been established.

For the purposes of this study, the following areas were examined: gender, educational attainment, disease severity, pain, satisfaction of support from a relationship with spouse or significant other, depressive symptomatology, income, and employment status. The
quantitative data examined in the present study was obtained by selecting items on the LEMPFSCD that were relevant for the present study. Eight questions were selected from the LEMPFSCD that represented the areas to be examined in the present study. Table 1 indicates the variables or concepts included in the present study, the instrument to which the variable or concept belongs, and reliability and validity for the instrument.

**Educational attainment.** Educational attainment was assessed in the LEMPFSCD using one open-ended item. Participants were asked to indicate, using a numerical value, the number of years of education received. The participants were provided examples to assist with converting education level into quantitative numbers. Specifically, the item read, “How many years of education do you have (examples: high school diploma or GED = 12 years, associate degree/training = 13-14 years, college graduate = 16 years, etc.)?” The participants indicated the number of years of education acquired based on the examples, with a high school diploma or GED equivalent to 12 years, an associate degree or technical training equivalent to 13 or 14 years, and a college degree equivalent to 16 years. The methodology implemented to assess educational attainment is an accepted method of assessing educational attainment within the field of psychometrics.

**Gender.** Gender was measured using forced-choice items within the paper-and-pencil measure. Participants indicated if they were “Female” or “Male”.

**Disease severity.** Disease severity was determined using participant response to the open-ended question “What type of sickle cell disease do you have?” Respondents who indicated they had SS or Sβ0 were coded as having severe forms of SCD, and Sβ+ and SC were categorized as mild (CDC, 2014). The two categories, either severe or mild, and were coded using 1’s or 0’s, respectively.
**Pain level.** Pain level was measured using the scores from the Short-Form McGill Pain Questionnaire (SF-MPQ) (Melzack, 1987). The present pain index (PPI) is a single question that summarizes the overall pain experience from 0 (no pain) to 5 (excruciating pain). The SF-MPQ is an assessment of both qualitative and quantitative aspects of pain. These aspects include location, quality, intensity, and temporality. The measure asked subjects to rate 15 pain-related descriptors on current intensity by circling none, mild, moderate, or severe. Three pain scores (sensory, affective, and total pain index) are then calculated. According to recent reviews of measurements of pain, the SF-MPQ is among the most frequently used self-rating scales for pain (Melzack & Katz, 2001). The SF-MPQ is used in research settings to collect data quickly about pain that is more in-depth than a simple indicator of pain intensity. The SF-MPQ includes 15 descriptors that are each rated by the user on a scale of intensity of 0 to 3 (0 = none, 3 = severe) (Melzack, 1987). There are 11 sensory components and affective components in the scale. Intensity values are summed for the categories of sensory, affective, and total to produce pain scores. A visual analogue scale (VAS) is also included in the SF-MPQ. A VAS is used to assess spontaneous pain and consists of a 100-mm line with “no pain” written at one end and “worst imaginable pain” written at the opposite end. The measurement of the individual’s pain is calculated by measuring the distance in millimeters from the no-pain end to the individual’s mark on the line.

**Satisfaction with support in a relationship.** Satisfaction with support in a relationship was assessed using the Alford-Edwards Social Support Inventory (AESSI) (Edwards et al., 2006) included in the LEMPFSCD (Pells et al., 2005). The AESSI was developed in response to the need for an empirically based and psychometrically sound measure of social support satisfaction for use with participants with chronic pain. The
AESSI, a 24-item measure, was constructed to assess participant satisfaction with four theory-driven components of social support—Emotional, Instrumental, Informational, and Comparison—common to participants with chronic pain. Each participant was asked to respond to the AESSI items asking how often the specific type of support was received. The participants used a five-point Likert scale in which a score of 4 indicated the highest level of support (all of the time) and a score of 0 indicated the lowest level of support (none of the time). The internal consistency of the AESSI was explored by computing Cronbach’s alpha using a sample of 67 adult participants with SCD. The computed Cronbach’s alpha for the overall AESSI score was 0.93, while alphas for AESSI subscales ranged from 0.86 (Informational Support) to 0.91 (Total Support Index). Correlations between the overall AESSI score and the AESSI subscales ranged from -0.11 (Frequency of Contact with Support Persons) to 0.99 (Total Support Index). For the current study, satisfaction with support from a spouse or significant other was summed of the four components of social support for the “Spouse/Significant Other” scale.

**Depressive symptomatology.** Endorsement of symptoms of depression was assessed using the Beck’s Depression Inventory (BDI) (Beck, Steer, & Carbin, 1988). The BDI is a common, well-known clinical measure of depressive symptomatology for psychiatric and non-psychiatric patients and has evidenced high levels of internal consistency and concurrent validity with other measures of depression. The BDI is a brief paper-and-pencil self-report measure consisting of 21 questions (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Questions in the BDI assess an individual’s depressive symptomatology. Respondents endorse one of four forced-choice responses for each of the 21 questions. Based on the endorsement by the individual, a numeric value is assigned to every question’s response. The
sum of combined total of points from responses yield an overall assessment of depressive symptomatology. This overall score was utilized in the present study. The BDI has been determined to be an effective measure for assessing depressive symptomatology within the general population when compared to two other popular measures (Aalto, Elvainio, Kivimaki, Uutela, & Pirkola, 2011). BDI scores demonstrate “good discriminant validity as measures of depression” (Aalto et al., p. 160) and have also been shown to demonstrate a high level of reliability.

**Income.** Income, one component frequently used to determine SES, was assessed using a forced-choice item completed by the participants. Participants were asked to indicate their salary range from the previous year by selecting from four different salary ranges. The item read “In what range was your salary last year?” The participants indicated their response by selecting one of the following ranges “$16,000 or less”, “$16,001-24,999”, “$25,000-54,499”, or “$55,000 or more”. Responses were coded as 1-4 in the data set.

**Employment status.** Employment status, a variable commonly used to determine SES, was assessed using a forced-choice item completed by the participants. Participants were asked to indicate their employment status by selecting from two choices. The item read “Are you currently employed?” The possible responses to the item were “yes” and “no”.

<table>
<thead>
<tr>
<th>Variable/Concept</th>
<th>Instrument</th>
<th>Reliability Data</th>
<th>Validity Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Attainment</td>
<td>Self-Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Self-Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease Severity</td>
<td>Self-Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>Self-Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td>Self-Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Severity</td>
<td>Short-Form McGill Pain Questionnaire (SF-MPQ; Melzack, 1987)</td>
<td>$\alpha: .88-.91$ (Kachooei et al., 2015)</td>
<td>$r: .43-.88, p &lt; .001$ (Kachooei, 2015)</td>
</tr>
<tr>
<td>Depressive Symptomatology</td>
<td>Beck Depression Inventory (BDI)</td>
<td>$\alpha = .90$ (Grothe et al., 2005)</td>
<td>$t(218) = 12.83, p &lt; .01$ (Grothe, 2005)</td>
</tr>
<tr>
<td>Relational Support</td>
<td>Alford-Edwards Social Support Index (AESSI)</td>
<td>$\alpha = .93$ (Edwards, 2006)</td>
<td></td>
</tr>
</tbody>
</table>

**Data Analysis**

A data set was derived from the original data set after a preliminary examination of the data indicated problems related to missing data. The data set was created by including participants with valid responses for the outcome variables of interest: depression, pain severity, relational support, income, and employment status.

Analysis began with an examination of the descriptive statistics for the overall sample (Table 2). Bivariate correlations were then calculated to assess initial associations among age, gender, educational attainment, disease severity, pain, depression, relational support, income, and employment status (Table 3). Three research questions were posed to examine the effects...
of the three independent variables on five dependent variables. To investigate how well gender, educational attainment, and disease severity predicted depression, pain severity, relational support, income, and employment status, five hierarchical linear regressions were computed. Independent variables were entered in 3 blocks. Gender was added first (Model 1), then educational attainment (Model 2), and then disease severity (Model 3) in the final block.
CHAPTER IV: RESULTS

From the original 254 participants, data for N = 85 were retained for the present analyses. This contingent represents individuals who were part of a sub study focused specifically on the role of depression in SCD-related pain (Edwards, 2009; McDougald et al., 2008). Means, standard deviations, and Pearson correlation coefficients were computed for all study variables and are presented in Tables 2 and 3, respectively. The sample was composed of 43 men and 42 women. The age range was 18-70 and mean age was 32.98 ± 11.76 years which is a relatively advanced age range for individuals with SCD given that the life expectancy for a man with SCD is 42 years and for a woman is 48 years (Platt, 1994). Mean level of education was 13.61 ± 1.91 years for the entire sample, 13.40 ± 1.91 years for men and 13.81 ± 1.92, for women, respectively. Overall, the sample had a higher level of education than the national average of individuals with SCD (Farber, 1985). In the sample, 29% (n = 25) were classified as having mild SCD, and 71% (n = 60) were classified as having moderate to severe SCD. Research has shown that individuals with severe forms of SCD are likely to adhere to medical guidelines, which includes regular preventative care, and may explain the higher percentage of individuals with severe forms of SCD in the present study (Quinn, 2010).
Table 2  
*Descriptive Statistics of Demographic and Measurement Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Range</th>
<th>Mean or %</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>85</td>
<td>18-70</td>
<td>32.98</td>
<td>11.76</td>
</tr>
<tr>
<td>Gender</td>
<td>85</td>
<td>1-2</td>
<td>1 = 51.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education (years)</td>
<td>79</td>
<td>9-18</td>
<td>13.61</td>
<td>1.91</td>
</tr>
<tr>
<td>Dis. Sev. (phenotype)</td>
<td>85</td>
<td>0-1</td>
<td>0 = 29.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (BDI)</td>
<td>85</td>
<td>0-36</td>
<td>9.40</td>
<td>7.94</td>
</tr>
<tr>
<td>Pain (SFMPQ)</td>
<td>84</td>
<td>0-5</td>
<td>3.66</td>
<td>1.31</td>
</tr>
<tr>
<td>Rel. Sup. (AESSI)</td>
<td>74</td>
<td>0-16</td>
<td>9.32</td>
<td>5.05</td>
</tr>
<tr>
<td>Income (dollars)</td>
<td>72</td>
<td>1-4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = 34.9%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 = 14.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 = 16.3%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 = 18.6%</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>83</td>
<td>0-1</td>
<td>0 = 60.0%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = Yes</td>
<td></td>
</tr>
</tbody>
</table>

*Note. Dis. Sev. = disease severity; Rel. Sup. = relational support.*

When bivariate correlations were examined, age was positively correlated with education ($r = .29$, $p < .001$). The relationship between age and education indicates that individuals who are older have more years of education while younger individuals have fewer years of education. Age was inversely correlated with disease severity ($r = -.26$, $p < .05$) and indicates that individuals who were older had lower disease severity than younger individuals who had higher disease severity. This may reflect the fact that individuals with higher disease severity often do not live to advanced age. Educational attainment was positively correlated with income ($r = .31$, $p < .001$) with individuals who had more years of
education having higher incomes than those with fewer years of education. Depression was positively correlated with pain ($r = .29, p < .001$) and indicated that high endorsement of depressive symptomatology was correlated with high endorsement of pain. Employment status was positively correlated with education ($r = .30, p < .01$) indicating that individuals who had more years of education were more likely to be employed than those with fewer years of education. Income was also positively correlated with employment status ($r = .29, p < .05$). Employment status and depression were negatively correlated ($r = - .24, p < .05$) indicating that being employed was associated with fewer symptoms of depression. These findings are consistent with previous research as individuals who are employed are more likely to have higher income levels and have higher levels of education. Also, as expected the correlations indicated that individuals with more severe depressive symptoms are likely to be employed at less than full-time. Correlations including gender were non-significant which was surprising as previous research indicated gender differences in the experience of pain.
Table 3
Bivariate Correlations

<table>
<thead>
<tr>
<th>Var.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2. Gen. (N)</td>
<td>.113</td>
<td></td>
<td>.108</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3. Ed. (N)</td>
<td>.288**</td>
<td>.311**</td>
<td></td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4. Inc. (N)</td>
<td>.143</td>
<td>-.113</td>
<td>.108</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5. Pain (N)</td>
<td>.077</td>
<td>-.104</td>
<td>-.068</td>
<td>.067</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6. Dep. (N)</td>
<td>.089</td>
<td>.039</td>
<td>.058</td>
<td>-.140</td>
<td>.289**</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>7. Rel. (N)</td>
<td>-.119</td>
<td>.007</td>
<td>-.088</td>
<td>.172</td>
<td>-.172</td>
<td>-.179</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>8. Dis. (N)</td>
<td>-.262*</td>
<td>-.188</td>
<td>.060</td>
<td>-.137</td>
<td>-.137</td>
<td>-.144</td>
<td>.061</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>9. Emp. (N)</td>
<td>-.109</td>
<td>.059</td>
<td>.300**</td>
<td>.286</td>
<td>-.031</td>
<td>-.235*</td>
<td>-.200</td>
<td>-.127</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. Gen. = gender; Ed. = educational attainment; Inc. = income; Dep. = depressive symptomatology; Rel. = relational support; Dis. = disease severity; Emp. = employment status. Pairwise deletion was used to address invalid cases. *p < .05; **p < .01.

A total of 5 hierarchical regression analyses were conducted for the outcome variables of pain, depression, relational support, income, and employment status. For each outcome, gender was entered as the primary predictor in Model 1, educational attainment was added in Model 2, and disease severity was entered as the final predictor in Model 3. Results are presented separately for each outcome in Tables 4-8.

Pain Severity

To investigate how well gender, educational attainment, and disease severity predict pain severity a hierarchical linear regression was computed. When gender was entered alone the model was not significant, $F(1,77) = .76, p = n.s.$, adjusted $R^2 = -.003$. As indicated by the $R^2$, less than 1% of the variance in pain severity could be predicted by knowing the
participant’s gender. When educational attainment was added the model was still not significant, $F(2, 76) = .51, p = ns$, adjusted $R^2 = -.01$. As indicated by the $R^2$ knowing the participant’s gender and educational attainment only accounted for 1% of the variance in pain severity. When gender, educational attainment, and disease severity were entered the model for pain severity was still not significant, $F(3, 75) = .96, p = ns$, adjusted $R^2 = -.002$. A review of the beta weights, presented in Table 4, indicates that, none of the variables significantly contribute to the model. The findings indicate that the models used in this study did not predict pain on the basis of gender, educational attainment, or disease severity.

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SEB$</th>
<th>$β$</th>
<th>$R^2$</th>
<th>$ΔR^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
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<tr>
<td>Gender</td>
<td>-.261</td>
<td>.299</td>
<td>-.099</td>
<td>-.010</td>
<td>.010</td>
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<tr>
<td>Constant</td>
<td>4.058</td>
<td>.477</td>
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<td>Step 2</td>
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<td>.013</td>
<td>.003</td>
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<tr>
<td>Gender</td>
<td>-.244</td>
<td>.302</td>
<td>-.093</td>
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<tr>
<td>Education</td>
<td>-.040</td>
<td>.079</td>
<td>-.058</td>
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<tr>
<td>Constant</td>
<td>4.582</td>
<td>1.137</td>
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</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td>.037</td>
<td>.024</td>
</tr>
<tr>
<td>Gender</td>
<td>-.316</td>
<td>.305</td>
<td>-.120</td>
<td></td>
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</tr>
<tr>
<td>Education</td>
<td>-.032</td>
<td>.079</td>
<td>-.046</td>
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</tr>
<tr>
<td>Severity</td>
<td>-.443</td>
<td>.326</td>
<td>-.157</td>
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</tr>
<tr>
<td>Constant</td>
<td>4.878</td>
<td>1.151</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .01.

**Depressive Symptomatology**

To investigate how well gender, educational attainment, and disease severity predict depressive symptomatology a hierarchical linear regression was computed. When gender was entered alone the model was not significant, $F(1, 77) = .40, p = ns$, adjusted $R^2 = -.01$. As indicated by the $R^2$, only 1% of the variance in depressive symptomatology could be
predicted by knowing the participant’s gender. When educational attainment was added the model was still not significant, $F(2,76) = .30, p = ns$, adjusted $R^2 = -.02$. As indicated by the $R^2$, knowing the participant’s gender and educational attainment only accounted for 2% of the variance in depressive symptomatology. When gender, educational attainment, and disease severity were entered, the model for depressive symptomatology was still not significant, $F(3,75) = .996, p = ns$, adjusted $R^2 = .00$. A review of beta weights, presented in Table 5, indicates that, none of the variables contributed significantly to the model.

Table 5

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>$R^2$</th>
<th>$Δ R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td>.005</td>
<td>.005</td>
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<td>Gender</td>
<td>1.076</td>
<td>1.696</td>
<td>.072</td>
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<tr>
<td>Constant</td>
<td>7.556</td>
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<tr>
<td>Step 2</td>
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<td>.003</td>
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<td>Gender</td>
<td>.994</td>
<td>1.715</td>
<td>.067</td>
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<td>Education</td>
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<td>.451</td>
<td>.051</td>
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<tr>
<td>Severity</td>
<td>-2.850</td>
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<tr>
<td>Constant</td>
<td>6.863</td>
<td>6.521</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .01.

Perceived Relational Support

To investigate how well gender, educational attainment, and disease severity predict relational support, a hierarchical linear regression was computed. When gender was entered alone the model was not significant, $F(1,67) = .02, p = ns$, adjusted $R^2 = -.02$. As indicated by the $R^2$, 2% of the variance in relational support could be predicted by knowing the participant’s gender. When educational attainment was added the model was still not significant, $F(2,66) = .26, p = ns$, adjusted $R^2 = -.02$. As indicated by the $R^2$, knowing the
participant’s gender and educational attainment accounted for 2% of the variance in
relational support. When gender, educational attainment, and disease severity were entered
the model for relational support was still not significant, \( F(3,65) = .33, p = \text{ns}, \text{ adjusted } R^2 = -
.03 \). As indicated by \( R^2 \), knowing the participant’s gender, educational attainment, and
disease severity accounted only for 3% of the variance in relational support. A review of the
beta weights, presented in Table 6, indicates that none of the variables contributed
significantly to the model.

Table 6
Hierarchical Multiple Regression Analysis Summary for Gender, Education, and
Severity, Predicting Relational Support (n = 69)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>( \beta )</th>
<th>( R^2 )</th>
<th>( \Delta R^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.186</td>
<td>1.243</td>
<td>-.018</td>
<td>.000</td>
<td>.000</td>
</tr>
<tr>
<td>Constant</td>
<td>9.767</td>
<td>2.025</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td>.008</td>
<td>.007</td>
</tr>
<tr>
<td>Gender</td>
<td>-.039</td>
<td>1.266</td>
<td>-.004</td>
<td>.008</td>
<td>.007</td>
</tr>
<tr>
<td>Education</td>
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<td>.335</td>
<td>-.087</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>12.728</td>
<td>4.680</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td>.015</td>
<td>.007</td>
</tr>
<tr>
<td>Gender</td>
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<td>1.284</td>
<td>.009</td>
<td>.015</td>
<td>.007</td>
</tr>
<tr>
<td>Education</td>
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<td>.337</td>
<td>-.090</td>
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<td></td>
</tr>
<tr>
<td>Severity</td>
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<td>1.337</td>
<td>.087</td>
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<tr>
<td>Constant</td>
<td>11.997</td>
<td>4.814</td>
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</tbody>
</table>

*\( p < .05 \); **\( p < .01 \).

Income

To investigate how well gender, educational attainment, and disease severity predict
income, a hierarchical linear regression was computed. When gender was entered alone the
model was not significant, \( F(1,67) = 1.43, p = \text{ns}, \text{ adjusted } R^2 = .01 \). As indicated by the \( R^2 \),
only 1% of the variance in income could be predicted by knowing the participant’s gender.
When educational attainment was added, the model was significant, \( F(2,66) = 4.85, p = .011, \)
adjusted \( R^2 = .10 \). As indicated by \( R^2 \), knowing the participant’s gender and educational
attainment accounted for 10% of the variance in income. When gender, educational
attainment, and disease severity were entered in the model for income the model was
significant, $F(3,65) = 4.24$, $p = .008$, adjusted $R^2 = .13$. As indicated by the $R^2$, knowing the
participant’s gender, educational attainment, and disease severity accounted for 13% of the
variance in income. A review of the beta weights, presented in Table 7, suggest that gender,
educational attainment, and disease severity entered together best predict income with
educational attainment significantly contributing to the model. The present study found that
the model including gender, educational attainment, and disease severity was best able to
predict income in adults with SCD.

Table 7
Hierarchical Multiple Regression Analysis Summary for Gender, Education, and
Severity, Predicting Income (n = 69)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
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<td>-.145</td>
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<td>.021</td>
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<tr>
<td>Constant</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.128</td>
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<tr>
<td>Gender</td>
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<td>.258</td>
<td>-.177</td>
<td></td>
<td>.107</td>
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<tr>
<td>Education</td>
<td>.190</td>
<td>.066</td>
<td>.329**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>.111</td>
<td>.969</td>
<td></td>
<td></td>
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<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.164</td>
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<tr>
<td>Gender</td>
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<td>.261</td>
<td>-.220</td>
<td></td>
<td>.036</td>
</tr>
<tr>
<td>Education</td>
<td>.201</td>
<td>.066</td>
<td>.349**</td>
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<td></td>
</tr>
<tr>
<td>Severity</td>
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<td>.283</td>
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<td></td>
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<tr>
<td>Constant</td>
<td>.428</td>
<td>.975</td>
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</tr>
</tbody>
</table>

*p < .05; **p < .01.

Employment Status

To investigate how well gender, educational attainment, and disease severity predict
employment status, a hierarchical linear regression was computed. When gender was entered
alone the model was not significant, $F(1,76) = .07$, $p = ns$, adjusted $R^2 = -.01$. As indicated by
the $R^2$, less than 1% of the variance in employment status could be predicted by knowing the
participant’s gender. When educational attainment was added, the model was significant, $F(2, 75) = 3.71$, $p = .029$, adjusted $R^2 = .07$. As indicated by $R^2$, knowing the participant’s gender and educational attainment accounted for 7% of the variance in employment status.

When gender, educational attainment, and disease severity were entered in the model for employment status the model was significant, $F(3, 74) = 2.89$, $p = .041$, adjusted $R^2 = .07$ but there was no change in $R^2$. As indicated by the $R^2$, knowing the participant’s gender, educational attainment, and disease severity accounted for 7% of the variance in employment status. Beta weights, presented in Table 8, suggest that gender, educational attainment, and disease severity entered together best predict employment status with educational attainment significantly contributing to the model. The present study found that the model including gender, educational attainment, and disease severity was significant in predicting employment status in adults with SCD.

Table 8  
Hierarchical Multiple Regression Analysis Summary for Gender, Education, and Severity, Predicting Employment Status ($n = 78$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SEB$</th>
<th>$\beta$</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
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</thead>
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<td>Step 1</td>
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<td>.030</td>
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<td>.031</td>
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<td>.001</td>
</tr>
<tr>
<td>Constant</td>
<td>.364</td>
<td>.180</td>
<td>**</td>
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<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td>.090</td>
<td>.089</td>
</tr>
<tr>
<td>Gender</td>
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<td>-.005</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>.078</td>
<td>.029</td>
<td>.301**</td>
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<tr>
<td>Constant</td>
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<td></td>
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<tr>
<td>Step 3</td>
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<td></td>
<td></td>
<td>.105</td>
<td>.015</td>
</tr>
<tr>
<td>Gender</td>
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<td>.111</td>
<td>-.028</td>
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<td></td>
</tr>
<tr>
<td>Education</td>
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<td>.029</td>
<td>.312**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severity</td>
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<td>-.123</td>
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</tr>
<tr>
<td>Constant</td>
<td>-.558</td>
<td>.416</td>
<td></td>
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</tr>
</tbody>
</table>

*p < .05; **p < .01.
CHAPTER V: DISCUSSION

The purpose of this study was to investigate the contribution of gender, educational attainment, and disease severity to predict depressive symptoms, pain, relational support, income level, and employment status in a sample of adults with SCD. The focus was on the role of education to predict later life outcomes while accounting for gender and disease severity, both of which had demonstrated impacting outcomes of individuals within the SCD population. Hierarchical multiple regression analyses were conducted to determine the extent to which three models predicted life outcomes of depressive symptoms, pain, relational support, income, and employment status. In Model 1 gender was entered alone, in Model 2 gender and educational attainment were entered, and in Model 3 gender, educational attainment, and disease severity were entered.

In the present study, the models predicting depressive symptoms, pain, and relational support were not significant. Models predicting income and employment status, however, were significant but the effect was minimal. Gender alone did not predict a significant portion of variance for any of the outcomes. This is in contrast to previous findings that demonstrated that gender was correlated with outcome variables (Akinsheye, 2011; McClish, 2006; Pegelow, 1997; Phebus, 1984; Platt, 1994). Education and disease severity did significantly predict income and employment status, but did not significantly predict depression, pain, or relational support. The results of the present study are compared to previous findings below and organized by outcome variables.
There was no significant effect of gender, educational attainment, and disease severity in the prediction of depressive symptoms. The lack of significant effect in the current study is in contrast to findings of previous studies. Previous studies on SCD and the role of gender found that men and women fared differently based on the outcome being assessed. According to Breslin et al. (2006), men with SCD experience a more severe impact of depression than women. However, Hasan (2003) found women with SCD to have higher rates of depression than men. Educational achievement also was not a significant predictor of depressive symptoms in the present study. Previously, Cutler (2010) found that increased educational attainment was linked to improved later life outcomes in a non-SCD population and should, therefore, protect against depression. Smith (2001) found that disease severity was negatively associated with psychosocial factors supporting findings of Schaeffer (1999) who found disease severity and depression to be related when examining SCD patients. The present study did not account for variance in depressive symptoms using the predictor variables. The present study may indicate that educational attainment within SCD does not protect against depression as well as in other populations. Further research may be required to identify factors contributing to depressive symptoms within this population.

The present study found no significant effect of gender, educational attainment, and severity on the prediction of pain. The findings of the present study are not consistent with findings of previous research for effects of pain in persons with SCD in which McClish (2006) found that men and women varied in the duration of pain crises and their frequency of medical service utilization. Results of the present study could not be compared to results of previous studies of the role of educational attainment on pain as such studies were not found for persons with SCD. However, pain has previously been studied in relation to school
participation. Eccleston (1999) found that increased pain in persons with SCD led to decreased school attendance and educational attainment. Similar to the findings of a lack of effect of gender on pain, the results from the present study for disease severity are in contrast to findings related to physical symptoms. Disease severity has previously been associated with physical impacts including organ failure and death (Strouse, 2006). However, impacts were not observed in the present study as there was a lack of effect for disease severity on pain. Findings of the present study were dissimilar to previous research to account for variance in reported pain of persons with SCD in that gender, educational attainment, and disease severity did not predict pain. Future research may examine other variables that may better explain the experience of pain within the SCD population.

The present study found no significant effect for gender, educational attainment, and disease severity in predicting relational support. These findings, similar to outcomes of depressive symptoms and pain, are inconsistent with previous research. Previously, Midence (2011) found that chronic health conditions had negative impacts on interpersonal relationships whereas Horner (2001) found that high levels of support in relationships resulted in better health. The present study demonstrated a lack of effect of disease severity on relational support. Factors contributing to relational support among individuals with SCD should be examined in future research.

The model including gender, educational attainment, and disease severity significantly predicted income. In contrast to previous findings, the present study demonstrated no significant effect for gender on income. Previously, Farber (1985) found gender differences in income for men and women where men with SCD earned less than their healthy counterparts but women with SCD had earnings similar to healthy counterparts.
Educational attainment in persons with SCD has been found to be positively correlated to income (Barro, 2013). In the present study, the more severe an individual’s disease, the lower their earnings, which is consistent with previous research. Lower wages can be expected as the ability to work is negatively impacted by the increase in disease severity (Ward, 2008). Although no significant effect was found in the present study for gender on income, educational attainment and disease severity significantly predicted income, which is consistent with previous research. Findings of the present study may provide an area of intervention to promote the later life outcome of income level for those with SCD as improving educational attainment may improve an individual’s earning potential.

Findings related to prediction of employment status were similar to those for income. Gender and disease severity were not found to be significant predictors of employment status in the present study, but educational attainment was significantly predictive of employment status in the full model. Educational attainment has been linked to an individual’s ability to gain employment (Barro, 2013). The findings in the present study support the possibility that educational attainment has a similar effect on employment status for individuals with SCD as for healthy individuals. SCD has been shown to decrease an individual’s ability to attend work regularly. Decreased attendance may be due to illness, appointments for medical treatments, or medical maintenance. Individuals with severe forms of SCD are more likely to have higher rates of medical adherence, compared to individuals with mild forms of SCD, resulting in frequent attendance at medical appointments (Ward, 2008). As individuals with more severe forms of SCD attend appointments more frequently than those with mild forms, it can be expected that disease severity may impact employment status but it was not predicted by disease severity in the present study. Findings of the present study suggest that
employment status of an individual may be predicted by their educational attainment. As such, promoting educational attainment of persons with SCD during the school years may promote later life outcomes related to employment status.

Overall, income and employment status were the only dependent variables significantly predicted by educational attainment in a full model accounting for a significant but very small, amount of variance in each of these outcomes. Previous research indicates that individuals with SCD have difficulty maintaining employment due to frequent illness or treatment-related absences (Smith, 2001). The present study suggests that educational attainment may be a factor in predicting adult employment and income among individuals with SCD. This may be of significance in that research has indicated that the monthly cost of SCD management is approximately $1,500 (Kauf, 2009) and the burden of SCD related medical expenses may be mitigated by the ability to maintain employment. Financial stability associated with employment status may lead to better healthcare outcomes and decreased stress due to financial burdens. Based on the findings of the present study, additional research may useful to further examine specific aspects of the relationship of education on income and employment status within SCD. Further, the findings of the study may suggest efforts to promote resilience within the SCD population through interventions designed to promote economic stability and improved SES through academic attainment.

Previous research has documented the importance of educational attainment on health outcomes, citing that it serves as a protective factor against the impact of disease (Ross, 1996; Cutler, 2006). Educational attainment increases an individual’s likelihood to participate in recommended medical screenings and treatment (Ward et al., 2008) and for persons with SCD this would include adherence to care plans that include attendance at
medical appointments and use of medications such as hydroxyurea. Although higher levels of education typically correlate with positive health outcomes, this was not the case for pain or depression in the current study.

**Limitations and Future Directions**

The current study was conducted using archival data. Use of archival data has benefits but also has drawbacks. The benefits of using archival data include ease of access to existing data, with the cost of conducting research considerably lower than that of prospective studies (Jones, 2010). There are also several disadvantages to using archival data, including a fixed number of participants, previously defined variables, utilization of previously conceptualized models of the relationship between variables, inability to select measures that are consistent with novel conceptualizations, and inability to select for certain demographic characteristics within the sample (Shultz, Hoffman, & Reiter-Palmon, 2005).

The current study was conducted with less than 100 participants. A small sample size increases the likelihood that random variation in data may be falsely attributed to the independent variables (Hackshaw, 2008). Attempts to collect additional data were not possible as the study was part of an ongoing study, the Parental Substance Abuse, Chronic Pain, and Coping in Adult Patients with Sickle Cell Disease, and only previously collected data was available for analysis.

The inability to select measures for the current study was a limitation in that educational variables were predetermined. Education was conceptualized and collected as a continuous variable representing total years of formal education. Education can be quantified in other ways such as academic grade point average, number of years required to complete
high school, or number of absences from school in a typical year. Alternative methods of quantifying education in this study may have yielded different results.

The present study defined disease severity of SCD using conventions of the CDC (2014) that resulted in participants being divided into two groups, those with mild and severe SCD. As a result, the sensitivity of statistical measures may have been limited by the two categories of SCD severity. Dichotomizing the data, may have limited analysis of the variation within the data. Future research using disease type as defined by genotype (SS, Sβ0, Sβ+, and SC) rather than phenotypic disease severity (mild or severe) may result in increased ability to detect statistical differences between genotypes.

The participants in the present study were more educated and chronologically more mature than the pediatric or young adult samples typically used in SCD studies to explore educational effects. The results of the present study may therefore be different from other studies due to the advanced age of participants and their higher levels of academic attainment.

Findings from the current study contribute to the existing literature about potential protective factors for individuals with SCD. The results of this study indicate that educational attainment accounts for a small, but significant amount of variance in both employment status and income level within the sample. However, the participants with SCD in this study differ from participants in other studies who are typically characterized by academic difficulties, low academic attainment, and cognitive disorders (Schatz, 2005). The participants in the present study had a mean academic attainment close to the national average for African Americans and above that of the average individual with SCD, possibly due to the communities from which they were drawn. The limited variation in educational
attainment of the participants in the present study and high levels of educational attainment may have affected the results of the present study. As there was little variation in educational attainment for the participants, statistical differences may have been difficult to detect.

The characteristics of participants in the present study differ from previously studied adults with SCD and may have influenced the findings of the study. The average age of participants in this study was in the mid-30s, which is considered to be an advanced age for individuals with SCD given current life expectancy to be in the mid-40s for most (Figueiredo, 2013). The participants included in this study also had more years of educational attainment than required for a high school diploma, which is higher than the national average of individuals with SCD (Farber, 1985). This finding is relevant as educational attainment has been linked to SES (Ward, 2008); the present study found that income in persons with SCD was associated with increased educational attainment, similar to the general population (Braun, 2002). Educational attainment may serve as a protective factor and decrease the impact of SCD on earning potential. Income and educational attainment are indicators of SES, individuals with high SES can access health insurance, community resources, and medical care, including treatment facilities (Ward, 2008), whereas individuals with lower SES may not have similar access. Further, participants in the current study did not vary greatly from one another in terms of educational attainment. The more restricted range in educational attainment may have made it more difficult to detect any differences in the outcome variables.

Participants in this study received their treatment from a teaching hospital, and not all individuals with SCD can access such a high level of care. Participants in the current study received care from Duke University Medical Center, which is a teaching hospital. According
to Ayanian and Weissman (2002), teaching hospitals provide a better overall quality of care than non-teaching hospitals. Teaching hospitals afford individuals access to new interventions delivered with high levels of fidelity, and individuals indicate that they receive better care than individuals treated in teaching hospitals. The perception of high levels of care by individuals at teaching hospitals along with new evidence-based interventions contribute to positive outcomes (Ayanian, 2002). The combination of higher educational attainment and access to high quality of health care differentiates the current study participants from those in previous studies with lower educational attainment and lesser access to community resources or teaching hospitals. The findings of this study therefore may not apply to all individuals with SCD.

**Implications for School Psychologists**

The results of the present study can inform the practice of school psychology in a number of ways and may offer insight into areas for future intervention within the SCD population. The findings indicate that a model with the variables of gender, educational attainment, and disease severity can predict income and employment status of persons with SCD. An implication of these results is for school psychologists to promote school attendance and academic achievement of children growing up with SCD.

School psychologists are encouraged by their professional associations, NASP and APA, to support all students and bolster protective factors (McCabe, 2007). In general, individuals with SCD are at risk for lower levels of academic attainment (Schatz, 2011). The present study found that educational attainment may be a protective factor for adults with SCD related to increased income and employment status. School psychologists can implement interventions with students with SCD to promote educational achievement as a
protective factor. Educational achievement is a well-known protective factor for all individuals and the strength of the protective factor increases as the individual ages (Lynch, 2003). The findings of the present study indicate that educational attainment may protect individuals from economic stressors typically experienced by persons with SCD. School psychologists can implement interventions to promote academic achievement of students with SCD.

The findings that academic attainment was predictive of income and employment should inform the practice of school psychologists when working with students with SCD to foster their educational attainment. Utilizing a systems level approach, school psychologists can design primary, secondary, and tertiary prevention to promote educational attainment for individuals with SCD. Primary prevention may include strategies such as informing all school staff of the academic risks faced by children with SCD. Such information should include common symptoms of stroke, silent infarct, and pain crises as well as how best to respond to such symptoms. Normalizing the occurrence of any chronic illness with in the schools through education may help decrease the negative stigma associated with illness and may increase willingness of students and families to disclose disease status. Reducing the stigma of illness may also help decrease the negative psychosocial impacts of SCD that may contribute to dropping out.

By increasing awareness of SCD the school staff may be better prepared to support students with SCD and identify those who may require secondary prevention. Secondary prevention activities may include identifying all children with SCD, tracking their academic progress and attendance, and providing supports to any student at risk of academic difficulties, or at risk of dropping out. Tertiary prevention should include student-specific
interventions for those with academic, medical, or psychosocial challenges. Such
interventions may include facilitating school attendance, promoting school completion by
implementing appropriate IEPs and transition plans (Johnsons, Stodden, Emanuel, Luecking,
& Mack, 2002). The forms of such preventions and their timing must be tailored to the
developmental, psychosocial, and academic needs of the student.

Children and youth with SCD present with unique challenges and risk factors that can
vary from one student to the next. Medical professionals should be consulted to determine
the level of impact of SCD on students’ ability to attend and to be academically engaged in
the classroom (Kaffenberger, 2006). Before additional interventions and preventions are
considered, it is necessary to determine if a child will be physically present in the school
building, as well as if there are any physical or neurological limitations that may impede their
attendance and participation (Dunn, 2004). Medical professionals and parents can be helpful
in determining the students’ current level of ability to participate in the school.

After the issue of school attendance in students with SCD has been addressed their
level of development in various domains should be evaluated. Children with SCD may
experience delayed social and physical development, and these delays can affect their ability
to function at a level commensurate with other students of similar chronological age
(Jenerette & Murdaugh, 2008). Environmental factors such as peer functioning should be
considered when designing interventions. Children with SCD are at risk for delayed sexual
maturation and delays can affect their peer relations due to obvious differences in physical
appearance (Edwards et al., 2007). Delays in cognitive functioning, maturity level, and
pubertal status may impact the ability of a student with SCD to participate fully in the
classroom. Developmental factors should be weighed when designing interventions to ensure
the interventions being implemented meet the unique needs of the student and are developmentally appropriate.

As SCD is a disorder that is passed from one generation to the next, students with SCD may experience stressors that students with other chronic illnesses may not. These stressors may be related to the impaired health of family members. Children with SCD have biological relatives with either sickle cell trait or SCD and may as a result experience financial and relational difficulties (Farber, 1985). When working with children with SCD it is important to establish that their most basic needs have been met. These needs include access to food, medication, transportation, and support of family. Families may not be resourced to meet these basic needs without the assistance of others. Social workers may help families with SCD in meeting basic needs.

School psychologists are well poised within schools to serve many functions including advocacy, consultation, assessment, and intervention (NASP, 2010). Early interventions by psychologists are strongly encouraged before the onset of academic, social, and behavioral struggles; these should continue throughout the child’s academic career and transition into the workforce or post-secondary education. Such interventions can mitigate the negative impact of SCD later in the person’s life in the form of protective factors as found in the present study. The school psychologist can help promote resilience of students with SCD through modifications of the environment, schedule, and curriculum that support their development. These supports do not necessarily require intensive time commitments but can have significant impacts on the child’s health, educational, and emotional development (Schatz, 2006). As condition severity varies among persons with
SCD it is important to communicate directly with the student’s physician to design appropriate interventions.

Environmental modifications by school psychologists can help support students with SCD. Students with SCD are likely to have complications associated with decreased blood flow due to constriction of blood vessels. Adjustments to the environment that may help students avoid these complications include access to water to avoid dehydration and avoidance of air conditioning vents that result in the constriction of blood vessels in the skin. Additional modifications include access to the restroom at any time due to an increased need to urinate and poorer kidney function compared to healthy peers. Seating near visual aids because of impaired eyesight, and proximity to the teacher to allow for monitoring of stroke symptoms are also environmental modifications. Students with SCD and a history of stroke are more likely to suffer additional strokes compared to those who do not have a history of stroke (Schatz, 2006).

Schedule modifications are environmental modifications that may alleviate fatigue, both cognitive and physical, felt by students with SCD. Students may require mental and physical breaks during the instructional day or even within tasks, with challenging subjects and tasks best scheduled at optimal times. Students recovering from hospitalization may be especially fatigued and will benefit from gradual re-entry into their schedule and coursework. Some students may require modifications of expectations in physical education courses as well as recreational times, including recess, field day, or field trips. These adjustments in the schedule, when appropriate, will serve as protective factors and may help students avoid additional complications of SCD.
Curricular modifications may help students avoid or recover from weaknesses that are common among students with SCD. Compared to typically developing peers, students with SCD are more likely to have difficulties in the areas of attention, reading, working memory, executive functioning, visual-motor skills, and memory. Additionally, students with SCD have a higher likelihood of being classified with a learning disability and often manifest socio-emotional difficulties (Hasan, 2003). Possible modifications to the curriculum include additional exposure to foundational skills in the areas of reading, study skills, learning strategies, and academic engagement behaviors. Students with SCD may also benefit from direct and explicit instruction to learn strategies to help them compensate for challenges in memory, attention, and social functioning. Behavioral interventions may also be appropriate based on the student’s needs. Early intervention such as reading interventions to ensure phonemic awareness or social skills training may help with existing challenges or mitigate the impacts of later difficulties resulting from SCD.

Students with SCD present unique challenges for school personnel who may be unaware of the many problems they face such as experience of pain, limitations in sustained attention, and history of stroke. School counselors should always be included in educational planning for students by providing information and recommendations to teachers about the behavioral and emotional needs of students with SCD. School psychologists can work with students and their parents to address their specific needs in school. Parents, with first-hand knowledge of their child’s strengths and needs, can play an integral role in designing and implementing changes necessary in the educational setting or the curriculum to support the child. Working together with parents, school personnel can advocate for, and support the school experience of students with SCD, thereby promoting their life outcomes.
REFERENCES


