

THE RELATIONSHIP AMONG SPIRITUALITY, SELF-EFFICACY,
AND QUALITY OF LIFE IN ADULTS
WITH SICKLE CELL DISEASE

by

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DEDICATION

I dedicate this Doctoral Dissertation to the loving memory of my parents who labored to develop my God-given talents. Today, I am a Nurse Scientist only because of their original love, care, and inspiration. I also salute the many nurse scientists who have blazed the trail and have allowed me to accomplish this dream. I endeavor to pass on what I have gained and to give back to others in the areas of nursing, healthcare and education.

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ABSTRACT

THE RELATIONSHIP AMONG SPIRITUALITY, SELF-EFFICACY, AND QUALITY OF LIFE IN ADULTS WITH SICKLE CELL DISEASE

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Context: For the individual with sickle cell disease (SCD), the lifespan is increasing but adults report decreased quality of life (QOL), low self-efficacy, and ineffective coping skills. The care of adult patients with SCD requires a complex multidisciplinary team approach with focus not only on physiological, psychological, and social needs, but also on spiritual needs. Quality of life, spirituality, and self-efficacy have been sparsely and separately studied in individuals with SCD. These three constructs have never been combined in one study in the adult SCD population.

Objective: The purpose of this study was to explore and describe the relationships among spirituality, self-efficacy, and QOL in adults with SCD. The specific aims were

to: 1) describe the relationships among spirituality, self-efficacy, and QOL in adults with SCD, and 2) explore variation in these relationships based on selected demographic characteristics.

Methods: This study used a descriptive correlational design. Prospective participants, 18 years and older, with SCD who receive services from Sickle Cell Disease Associations were invited to participate in the study through a mail out and electronic survey. The instruments that were used include the Functional Assessment of Cancer Therapy-General (FACT-G) to measure QOL, the Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp) to measure spirituality, and the Sickle Cell Self-efficacy Scale (SCSES) to measure self-efficacy.

Results: Individuals who reported high levels of spirituality and self-efficacy reported high levels of QOL. Reports of self-efficacy and spirituality predict QOL among adults with SCD. Spirituality and self-efficacy accounted for more than fifty percent, a significant amount of QOL variability. Spirituality accounted for 6.6%, and self-efficacy accounted for 34.6% of total variance in QOL. The analysis of variance (ANOVA) indicated no significant interaction between selected demographic variables and the study variables. There was strong correlation between spirituality, self-efficacy, and QOL, with correlation coefficients of .63 to .68.

Implications: This study provides information about the role that spirituality, self-efficacy, and QOL play in the lives of adults with SCD, and gives direction for developing holistic interventions with the inclusion of spirituality.

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CHAPTER 1

INTRODUCTION

Although individuals with chronic, genetic hemoglobinopathy, sickle cell disease (SCD) are living longer, they report decreased quality of life (QOL) (Anie, Steptoe, & Bevan, 2002; Maxwell & Streetly, 1998; Strickland, Jackson, Gilead, McGuire, & Quarles, 2001), low self-efficacy (Edwards, Telfair, Cecil, & Lenoci, 2000; Edwards, Telfair, Cecil, & Lenoci, 2001; Lenoci, Telfair, Cecil, & Edwards, 2002), lack effective self-care and coping skills (Comer, Meier, & Galinsky, 2004; Comer, 2004; Gil, Abrams, Phillips, & Keefe, 1989), and at times, perceive life as hopeless. The lives of these individuals may also be interrupted by unpredictable chronic and acute pain resulting in periodic entry into the acute healthcare system (Maxwell & Streetly, 1998; Maxwell, Streetly, & Bevan, 1999).

Sickle cell disease, like other chronic illnesses, is best managed by promoting holistic health and comprehensive self-care strategies that decrease hospitalization, increase psychosocial functioning (Anie & Green, 2004), minimize or prevent 'earlier' than expected deaths (Houston-Yu, Rana, Beyer, & Castro, 2003), and improve QOL (Acton & Malathum, 2000; Dorsey & Murdaugh, 2003). Self-care strategies are best illustrated as effective when the individual demonstrates self-efficacy, takes charge of life

situations, and has a strong conviction of being successful with the outcome (Dorsey & Murdaugh, 2003; Dorsey, Phillips, & Williams, 2001). Self-efficacy reflects the individual's desire and focus to achieve a determined level of health and QOL. Edwards et al. (2001) report that individuals with SCD who reflect high levels of self-efficacy also describe low levels of disease symptomatology.

Quality of life, the perception of being able to manage or balance health conditions, is based on individual perception and is related to personal ability and sense of self. Quality of life reflects the holistic balance in biophysical, psychological, socio-cultural, and spiritual dimensions of one's life. As Goddard (1995) points out, "western society has tripartitioned personhood into distinct biophysical, psychological and spiritual components and then banished the spiritual dimension to relative obscurity" (Goddard, 1995). For persons with SCD, the role of spirituality in promoting holistic care appears to have been mostly overlooked.

For the individual with SCD, because of better healthcare options and success of childhood antibiotic programs, expected lifespan is increasing. Improving QOL for individuals with SCD is of utmost importance to reduce illness states. To do so requires an understanding of QOL and factors that influence QOL for individuals with SCD.

Background and Significance

Incidence and Prevalence

Sickle cell disease, an inherited, autosomal, recessive group of blood disorders, is characterized by the production of sickle hemoglobin and affects approximately 72,000 individuals in the United States of America (USA). This is a major worldwide public

health problem with approximately 300,000 affected individuals born each year (Serjeant, 1997). This chronic, genetic condition, which primarily, although not exclusively, affects African Americans in the USA (Nash, 1994), is caused by a mutation that produces defective hemoglobin, with the potential for damage to all systems of the body.

In the USA, SCD is also found in people of other geographic origins: Caribbean, Mediterranean European, Middle Eastern, Asian, and East Indian. The origin of the disease is unclear, but mutation responsible for the disease has been traced to the African continent, specifically to central west Africa (Ohene-Frempong, 2004). While the early export of the sickle gene came largely through the forced migration of Africans to the Americas, the twentieth century spread has occurred largely through migration of individuals from developing countries voluntarily seeking better opportunities in more developed countries (Ohene-Frempong, 2004) and mass globalization.

With SCD, a monogenic or single gene disease, the primary dysfunction is formation of abnormal beta chains in the hemoglobin molecule that results in abnormal hemoglobin, hemoglobin S (HbS), within the red blood cells. With this dysfunction, there is a single base substitution in the gene encoding the human β -globin sub-unit with the resulting replacement of β_6 glutamic acid by valine (Bunn, 1997). The abnormal, sickle hemoglobin (HbS), when deoxygenated, forms polymers causing cell sickling and damage to the membrane. Some sickle cells adhere to endothelial cells leading to vaso-occlusion (Bunn, 1997; Steinberg, 1999).

The normal adult hemoglobin, hemoglobin A (HbA), usually comprises 98%-99% of the total hemoglobin, with a small percentage of fetal hemoglobin or hemoglobin

F (HbF) (Ignatavicius, Workman, & Mishler, 1999). In individuals with SCD, at least 50% of their total hemoglobin contains an abnormality of the beta chain, hemoglobin S (HbS). In individuals with sickle cell anemia (hemoglobin SS, HbSS), approximately 95% of their total hemoglobin is hemoglobin S. For those with sickle cell hemoglobin C (HbSC), the sickle hemoglobin is 50% of total hemoglobin (Frenette & Atweh, 2007). Sickle hemoglobin (HbS) is sensitive to changes in the oxygen content of the red blood cell (RBC).

Sickle cell syndromes include common genotypes of sickle cell disease: sickle cell anemia (HbSS), sickle cell hemoglobin C disease (HbSC), and sickle β Thalassemia. With these common variants, the inheritance pattern varies. In HbSS, the individual inherited a sickle (S) gene from each parent. In hemoglobin C (HbSC) disease, the individual inherited a S gene from one parent and a C gene from the other parent. In neither of these variants can normal hemoglobin (hemoglobin A) be produced. In sickle β -Thalassemia, the individual inherits a S gene from one parent and a β -Thalassemia gene from the other parent.

Sickle cell trait is not a part of sickle cell disease syndrome. With sickle cell trait, the individual has approximately 60% normal hemoglobin A. The individual receives one sickle hemoglobin gene from one parent and a normal hemoglobin gene from the other parent. Sickle cell trait is usually benign and under most conditions, the concentration of hemoglobin S does not form polymers that cause injury that result in symptoms such as those in SCD (Bunn, 1997; Steinberg, 1999).

Sickle cell disease is characterized by chronic hemolysis, vaso-occlusion, and marked variations in presentation and severity of symptoms among individuals. The abnormality with the red blood cells (RBCs) is the core problem that causes other systemic complications (Reed & Vichinsky, 1998). When RBCs containing large amounts of HbS are exposed to decreased oxygenated conditions, the abnormal beta chains contract, polymerize, clump together, and alter the shape of the erythrocytes. These distorted, elongated, sickled RBCs cluster and obstruct blood flow, resulting in tissue hypoxia, blood vessel obstruction, and tissue infarction (Ignatavicius et al., 1999).

With proper oxygenation and removal of precipitating conditions, sickled cells can resume normal outward appearances. Some of the internal hemoglobin, however, remain twisted, decreasing cell flexibility, and over time become irreversibly sickled. Additionally, cells with HbS become fragile and are easily destroyed by the spleen. The average lifespan of erythrocytes is 120 days, but erythrocytes with 50% or more HbS will survive for only 20 days. This capitated, reduced lifespan is responsible for the hemolytic anemia in individuals with SCD (Ignatavicius et al., 1999).

Diagnosis of SCD is generally made by three main methods: 1) during the prenatal period by chorionic villus or amniotic cell sampling and subsequent DNA sampling, 2) by newborn screening with blood obtained from a heel stick or umbilical cord sample, or 3) later in life through venous blood sample (Holbrook & Phillips, 1994).

Sickle cell disease is characterized by unexpected medical complications throughout the individual's life. These complications include unpredictable intermittent pain episodes (Alleyne & Thomas, 1994), stroke, osteomyelitis, hemolytic anemia,

priapism, aseptic necrosis, potential for blindness, cardio-pulmonary problems, infections, renal failure and major organ damage (Nash, 1994). The anemia, which begins at birth and becomes fully expressed by 4-6 weeks of age, is caused by rigidity of RBCs and their inherent tendency to sickle (Holbrook & Phillips, 1994). The fragility of the RBCs causes cellular destruction or hemolysis, and results in anemia. In addition to the anemia, vaso-occlusion, whereby blood flow is affected because of the sickled, deoxygenated condition of RBCs, also occurs. Over time, the inadequate oxygenation results in tissue and organ damage, and is evidenced by pain and sickle cell crisis.

Life with SCD

Pain, the hallmark of SCD that can be unrelenting and unpredictable, is the leading cause of emergency department visits and hospitalizations and is the major focus throughout the individual's life. This major presenting symptom of SCD is complex and poorly understood, and the experience can be different for each individual (Newcombe, 2002). Past, present and anticipated pain experiences influence the individual's response.

Most individuals with SCD experience a prodromal stage with a gradual increase of warning signs days and hours before a crisis. Patients often report that their pain is poorly managed when they are in the hospital (Elander, Lusher, Bevan, & Telfer, 2003) or that staff are not responsive to patients' reports of pain. Staff perceptions of patients' dependence on pain medications affect pain management and place the patient at risk for 'pseudo-addiction' (Weissman & Haddox, 1989), which increases the risk of further pain. Weisman and Haddox (1989) explained 'pseudoaddiction' as an iatrogenic syndrome of abnormal behavior developing as a direct consequence of inadequate pain management.

The individual develops feelings of anger and isolation that lead to acting-out behavior. The healthcare provider (HCP) perceives the patient as having a behavioral problem. The HCP initially is frustrated at not being able to control the patient's complaint of pain and becomes fearful of inducing drug tolerance or dependence. Over time, the HCP avoids contact with the patient as a means to reduce conflict with the patient. The patient begins to distrust the HCP. A vicious cycle stimulated by inadequate pain management results in 'pseudo-addiction' syndrome.

In 1973, the average life span of a patient with SCD was 14 years. Thirty years later, with the development of comprehensive care models, day hospitals, and ongoing clinical research, life expectancy of persons with SCD has increased to 50 years (Claster & Vichinsky, 2003). Advances in the management of SCD have dramatically changed the outlook for patients. Despite increased life span, individuals report decreased QOL, depression, and increased mortality at young ages (not living to expected years).

Houston-Yu et al. (2003) report that, "patients with SCD are not homogenous with respect to disease severity" (p. 2001), even within the same genotypic subset. In Houston-Yu et al.'s study, those patients who died had rated their future QOL as lower than those patients who were still living, and higher depression scores were found in the group of patients who died.

The 96 adults in Anie et al.'s (2002) study also reported poorer QOL than did the general population. The participants in Anie et al.'s study had particularly poor reports in the areas of vitality, health perception, and physical and emotional problems.

Participants in the 2002 National Institutes of Health-conducted focus groups identified religious/spiritual identification and participation as one of the seven essential concepts to evaluate in developing a QOL measure for SCD (Adults with sickle cell disease: Meeting unmet needs, 2002). Studies based on spirituality and religion among African Americans have concluded that African Americans tend to be highly spiritual by nature or culture (Conner & Eller, 2004; Cooper-Effa, Blount, Kaslow, Rothenberg, & Eckman, 2001; Harrison et al., 2005; Holt & McClure, 2006), and would benefit from culturally appropriate spiritual care. In one of the first published studies on religion/spirituality and pain in adult patients with SCD, Cooper-Effa et al. found that higher levels of religiosity were related to control of pain, but not to pain severity (Harrison et al., 2005).

Strickland, Jackson, Gilead et al. (2001), in summarizing the themes derived from their focus group, claim religion served as a coping insulator. Participants in their study reported the use of religion, going to church, and frequent praying to cope with the pain and stress of SCD. Religion was also highlighted as a mechanism for coping with the prospects of early death (Strickland et al., 2001). Among the same groups of participants, there was the indication of fear, worry, fatalism, and lack of vigilant self-care strategies that were attributed to concerns about disease sequela (p. 39-40). It remains unclear if the same individuals who expressed using religion as a coping strategy expressed these differences of fatalism, worry, and anxiety; however, it is clear that individuals with SCD report benefit from their spirituality.

It has not been clear in previous studies if the naturally occurring high level of religiosity in African Americans is the precipitating factor for inverse correlations of spirituality and pain severity. It would be important to distinguish between individuals with latent cultural belief from those with active religious commitment (Harrison et al., 2005). The manner in which spirituality is beneficial is debated, and may be a result of combined factors. George, Ellison, and Larson (2002), in referring to the connecting link to religion and health, concluded that some mediators include health practices, social support, psychological resources such as self efficacy, mastery and self-esteem, and sense of coherence or meaning. Combined mechanisms are likely contributors to spirituality. These contributors help individuals cope with illness, buffer stress, and improve health (Harrison et al., 2005).

Edwards et al. (2001) posited that self-efficacy beliefs among African American adults with SCD are inversely related to reported disease symptomatology, and the relationships persist across time. Self-efficacy for the management of chronic illness not only influences current states of symptoms, but also may affect the course of the disease (Edwards et al., 2001). Self-efficacy beliefs can influence disease management behavior in chronic illnesses (Clark & Dodge, 1999; Edwards et al., 2001; Gillis, 1993), and perceived efficacy plays a significant role in predicting adjustment to SCD (Edwards et al., 2000).

In their 12-month prospective cohort study, Edwards et al. (2001) used data gathered from 147 African American adults with SCD to investigate the impact of self-efficacy on short-term and long-term adjustments to the disease. The data reflected that

adults with SCD who reported lower levels of self-efficacy tended to report more physical and psychological SCD-related symptoms. These individuals reported more pain and more frequent physician visits than those individuals who reported relatively higher levels of self-efficacy. Over the one-year study period, there was stability in efficacy beliefs. Both Lenoci et al. (2002) and Jenerette (2004) report similar negative relationships between self-efficacy and healthcare services use. Lenoci et al. (2002) also report a negative relationship between self-efficacy and pain severity.

Theoretical Framework

The theoretical framework for this descriptive correlational study includes concepts from Adegbola's Quality of Life Model (Figure 1), which provides an understanding of chronic illnesses and related factors that affect QOL. The framework provides direction for the program of research needed to understand QOL among individuals with SCD and societal and healthcare interventions that will yield improved QOL for those with SCD.

Overall Description of the Model

Individuals with SCD are now living longer. Survival into adulthood is a relatively new phenomenon, and its associated QOL issues have not been adequately studied and understood (Strickland et al., 2001). The morbidity of SCD, however, is known to have negative effects on QOL (Ballas et al., 2006), and there is a need to employ an integrative management focus to attend to QOL issues.

Because of the physiological, psychological, social, and spiritual complexities of SCD and its accompanying illnesses, individuals with SCD should be managed with a

comprehensive chronic illness model that focuses on a biopsychosociospiritual perspective. Hiatt's (1886) biopsychosociospiritual perspective provides the basis for this model.

In this model, there are contributory environmental vulnerabilities, genetic predispositions, co-morbidities and attributes that may affect the QOL of the individual with SCD. Other concepts that affect QOL are self-efficacy, self-care, response shift, health literacy, chronic illness, and spirituality.

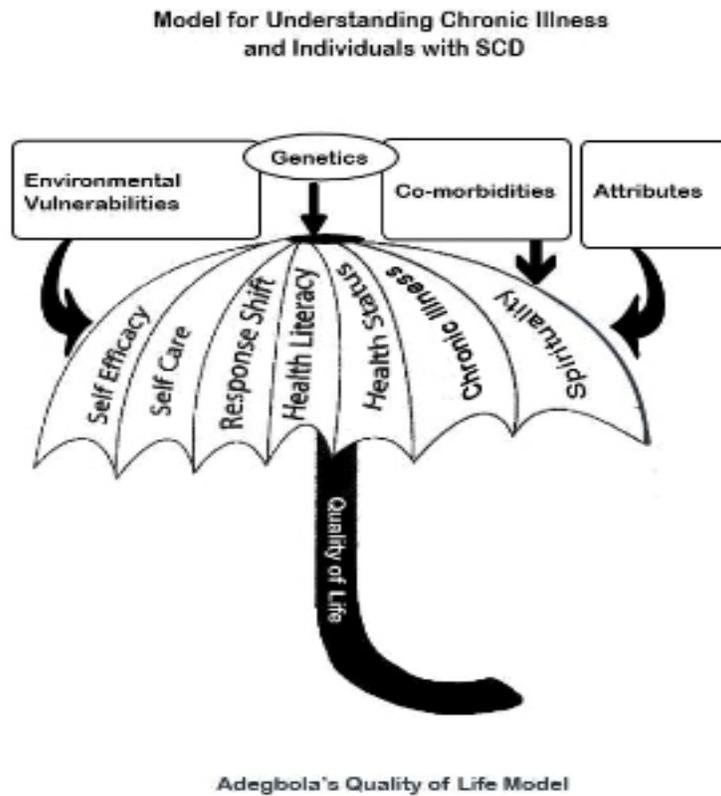


Figure 1. Adegbola's quality of life model

Because there is little research to guide understanding about QOL and associated factors among persons with SCD, more inquiry in QOL-related issues is needed. This study places special emphasis on the relationships between QOL, spirituality, and self-efficacy. These relationships among spirituality, self-efficacy, and QOL are depicted in Figure 2.

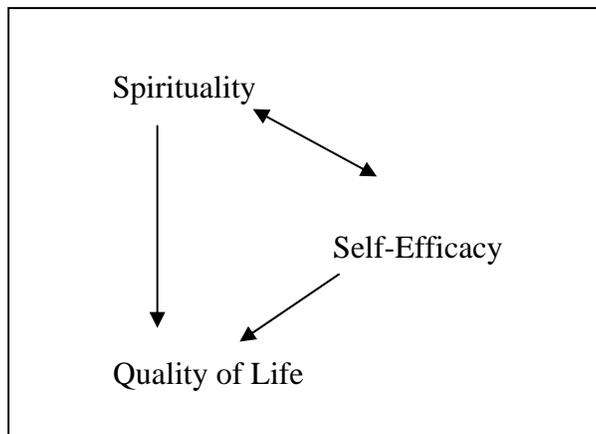


Figure 2. Model depicting relationship among QOL, spirituality, and self-efficacy

Definition of major study concepts

Quality of life.

In this study, QOL is defined as the individual's subjective, expressed interpretation of life events, and self-perception of well-being. The QOL view is based on the individual's statement and perception.

Quality of life is a complex, multidimensional construct. It is based on the individual simultaneously evaluating several dimensions of subjective experiences and

functioning to arrive at an overall judgment and evaluation of the meaning of such individual experiences and satisfaction with life. Quality of life (QOL) may be measured in terms of experience and expression of positive adjustment, successful performance of adaptive tasks, absence or negation of psychological disorder (Dinoff, 2002), and individual evaluation of the situation within the context of expectations and experiences (Schlenk et al., 1998) . Quality of life is a rich, robust, outcome-driven construct that has both objective and subjective components intertwined and interlocked. There is, however, a lack of a standard definition of QOL with resulting difficulty to generalize findings across studies. Researchers and authors agree that QOL as a construct is multidimensional, but few agree on the necessary components that are subsumed under QOL.

Historically, the QOL concept began with Aristotle, who conceived QOL as happiness and a good life (Anderson & Burckhardt, 1999; King & Hinds, 1998). Within the context of healthcare, QOL is still outcome-driven, as it is perceived to be affected by factors over which nurses have some control. Some of these factors are symptom management and personal and social issues (King & Hinds, 1998).

In healthcare, there has been a shift in focus from acute, infectious diseases to chronic illnesses that result in burden and a negative effect on health-related life (Schlenk et al., 1998); hence, it is important to determine QOL in the context of chronicity when a cure is not possible (Burckhart & Anderson, 2003; Murdaugh, 1997). The terms QOL and health-related QOL (H-RQOL) will be used interchangeably in this study.

The individual's psychological outlook in the presence or absence of physiological burden can be the deciding factor in expressing QOL. There are many dimensions of life and states of well-being, which are not necessarily related to the absence of disease, or the report of decreased health status. In other words, an individual can have an illness or medical diagnosis and yet have and enjoy a high QOL. The valuation that the individual places on life is just that- individual and subjective. The converse is true; an individual can have total functional abilities, yet report decreased QOL.

Self-efficacy.

Self-efficacy in the overall management of chronic diseases reflects the individual's beliefs, abilities, and motivation to integrate cognitive, spiritual, social, and behavioral skill sets. These skill sets assist the individual to effectively deal with and manage the complexities and sequela that accompany chronic diseases and thus achieve desired outcomes (Clark & Dodge, 1999; Edwards et al., 2001; Gillis, 1993). Individuals with SCD must demonstrate self-efficacy, maintain motivation to remain well, and care for themselves

Spirituality.

Spirituality, a sense of self, is a synthesis of personal, self-expressed beliefs and activities of essence of being that balances and connects other dimensions and domains of human traits and health (Frey, Daaleman, & Peyton, 2005; Young & Koopsen, 2005). Spirituality and spiritual beliefs are interconnected to physical, social, and psychological domains and add balance to human existence. Apart from psycho-social

and physical variations of health, individuals with SCD experience spiritual variations of health such as hopelessness, negative self-talk, and fatalism. The fatalism persons with SCD experience results in the feeling that there is little that the individual can do to change the course of the disease, and actions for vigilant self-care are minimized because of despair (Strickland et al., 2001). It is essential to foster health maintenance in all domains. This domain was included in the model as spirituality frequently is not examined in chronic illness discussions (O'Connell & Skevington, 2005). Spirituality and spiritual health, however, are essential ingredients in remaining motivated and acting on the desire to maintain balanced and quality health outcomes, thus balancing life with a chronic disease.

The concepts of self-efficacy, spirituality, and QOL are all inter-connected and inter-related. Self-efficacy and spirituality are the motivating forces that activate and propel the individual's desire to maintain QOL and health status. Reciprocally, positive QOL will further motivate, and stimulate activation and maintenance of self-care management.

Purpose and Research Questions

The purpose of this study was to explore and describe the relationships among spirituality, self-efficacy, and QOL in adults with SCD. It is essential to examine these combined constructs in one study. No single study has examined relationships among these concepts. Few have examined the role of QOL in adults with SCD. Such knowledge is needed to guide the development of interventions for persons with SCD.

The specific aims of the study are to:

1. Describe the relationships among spirituality, self-efficacy, and perceived QOL in adults with sickle cell disease.
2. Explore variation in these relationships based on selected demographic characteristics of age, gender, household income, levels of education, frequency of hospitalization, and reported SCD genotype.

The primary hypotheses to be examined are:

1. Hypothesis one: There is a positive relationship between spirituality and QOL in adults with SCD.
2. Hypothesis two: There is a positive relationship between self-efficacy and QOL in adults with SCD.
3. Hypothesis three: There is a positive relationship between self-efficacy and spirituality in adults with SCD.
4. Hypothesis four: Spirituality and self-efficacy predict QOL for adults with SCD

Definitions

For the purpose of this study, the following will serve as theoretical and operational definitions.

Self-efficacy

Self-efficacy is the belief in one's capabilities to enable and execute a course of action for a required task. In this study, self-efficacy is depicted by responses on the Sickle Cell Self-efficacy Scale (SCSES) (Edwards et al., 2000).

Spirituality

Spirituality is a synthesis of personal, self-expressed beliefs and activities of essence of being that balances and connects other dimensions and domains of human traits and health. Spirituality and spiritual beliefs are interconnected to physical, social, and psychological domains and add balance to human existence. In this study, responses on the Functional Assessment of Chronic Illness Therapy–Spiritual (FACIT-Sp) (Peterman et al., 2002) serve as the measurement of spirituality.

Quality of life

Quality of life is the individual's expressed interpretation of life events and self-perception of well-being. In this study, QOL is defined by responses on the Functional Assessment of Cancer Therapy-General (FACT-G) (Cella et al., 1993).

Assumptions

For this study, the following assumptions are made:

1. Self-efficacy is not restricted by knowledge of self-care strategies.
2. Self-efficacy is not restricted by health status.
3. Religious affiliation is not a necessary component of spirituality.
4. Spirituality is a unitary construct influenced by but not dependent upon one's biopsychosocial health.

Summary

Sickle cell disease predominantly affects African Americans and individuals of the African Diaspora, whose traditional religious heritage and spirituality influence cultural practices (Pearson, 1994). To understand QOL among these individuals with SCD requires an understanding of their spirituality and self-efficacy.

Spirituality provides an enhanced and strengthened sense of self that gives hope for positive future outcomes (Dyson, Cobb, & Forman, 1997). The individual knows that he possesses the “capacity of inner strength, being, knowing, and doing,” and these resources are “always present” (Coyle, p. 590).

Spirituality then can benefit health by providing meaning and purpose by engendering a positive state of mind, which in turn encourages healthy behaviors and promotes peace, hope, and self-confidence that ultimately contribute to disease prevention and recovery (Coyle, 2002; Frey et al., 2005). Spirituality then promotes the pursuit of well-being that provides hope, support, stability, and gives direction in critical times (Hill & Pargament, 2003). Matheis, Tulskey et al. (2006) also identified spirituality as a contributor to the sense of hope, optimism about one’s present and future life. Reicks, Mills, and Henry (2004) identified spiritual practices such as prayer and scripture reading increased confidence and self-efficacious behaviors. With increased optimism, there is an increased positive assessment of overall well-being, and ability to achieve positive outcomes, that is to be self-efficacious. “People with a sense of meaning and purpose survive more readily in difficult circumstances” (Narayanasamy, 2004, p.1141).

The proposed study will provide information about the role that the concept of spirituality plays in the life of adults with SCD and how each relates to self-efficacy. The study will give direction for further inquiry. Understanding these relationships is important to the development of comprehensive and effective care strategies for those with chronic illness and especially those with SCD.

CHAPTER 2

REVIEW OF LITERATURE

Overview

This chapter presents the review of relevant literature. The first section on Quality of Life (QOL) describes the significance of QOL as an end-point. In the second section, the concept of spirituality and its relationship with QOL are described and explored. Self-efficacy and its relationship with QOL and spirituality are discussed in the next section.

This study will increase the body of QOL, self-efficacy, and spirituality literature as it pertains to individuals with SCD specifically, and chronic illness generally. There is no known study that has examined the combined relationship among QOL, self-efficacy, and spirituality in individuals with Sickle Cell Disease (SCD). With the increased knowledge, QOL related issues can be explored and health promotion plans can be instituted for those persons with SCD.

Reviewing each construct as a separate entity was the approach used for the review of literature. The organization of this chapter includes a presentation of each concept followed by studies associated with each concept and conducted among persons with SCD. Following this is a review of tools to measure each concept among persons with SCD.

Quality of Life

Quality of life is dynamic (Murdaugh, 1997) and changes over the course of life. The evidence of these changes may be so amazing that healthcare providers and others are unable to appreciate these changes as valid. “Healthy people generally underestimate the self-reported well-being of people with disabilities and serious illnesses” (Riis et al., 2005, p.3, abstract). Possibly, some of these changes in the individual’s perspective of life can be explained by response shift (Sprangers & Schwartz, 1999), shifting perspective (Paterson, 2001), and adaptation to condition (Riis et al., 2005).

So, whose life is it?

There is much discussion in the literature about circumstantial and environmental conditions dictating QOL (Haas, 1999b). Some authors and researchers have criticized the combination of QOL with the descriptor “health-related” as poor adhesion of terminologies, which leads to further murky explanations. Ferrans, Zerwic, Wilbur, and Larson (2005), however explain that the term, health-related quality of life (H-RQOL) was “intended to narrow the focus to the effects of health, illness and treatment on quality of life” (p. 336). Hence, non health-related aspects of QOL, such as social, cultural, and political attributes, are excluded from definitions and discussions in order to focus on experiences that directly affect health.

Quality of life is not necessarily a measure of functionality, but an individual’s appraisal of life circumstances (Lawton, 1999), and may, apart from having subjective judgments, contain objective evidence. According to Haas (1999a) from a personal communication with Leidy, functionality is measured objectively and can be physical,

psychological, social, or spiritual. Since it is the individual's QOL, subjectivity is more valid than is objectivity.

Lawton's (1999) multidisciplinary concept analysis of QOL presents a borderline case that exemplifies functionality, and an example of a scenario that easily can be confused with QOL. Quality of life is not necessarily about pure feelings, but has an encompassing, multidimensional drive that reflects the individual's functionality in dimensions that include physical, social, psychological, overall life satisfaction/well-being, health status perceptions, personal productivity, spirituality, intimacy, pain, and neuropsychological functioning (Naughton & Shumaker, 2003). For the individual who is able to make a rational decision and deems his/her situation to be an example of increased QOL, then it is so for the individual. Hence, interpretation of QOL is viewed as subjective.

Table 1 provides a summary of QOL studies among adults with SCD. The quantitative studies were conducted with the SF-36 as the measurement for QOL. Participants in all the studies reported poor QOL. In addition, Anie et al. (2002) in their study of 96 individuals with SCD, reported role limitations related to physical and emotional problems and general health perceptions, and lack of vitality. McClish et al. (2005) in their longitudinal study assessed whether SCD specific variables, such as pain, genotype, and crisis, were predictive of the SF-36 subscales. The authors concluded that individuals with SCD experience decreased QOL, which is inversely related to pain level.

In the qualitative studies, persons with SCD reported difficulty coping with physical pain that interfered with the individual's everyday task completion. Strickland et

al. (2001) reported on psychosocial burdens that hamper emotional adjustment and pain control. Some individuals reported coping with the pain by using religion and spirituality. Participants in Thomas and Taylor's (2002) study reported that pain affected their day-to-day activities, zapped their energy, and hampered physical aspects of QOL.

Table 1 QOL studies among adults with SCD

Source	Purpose/ problem	Sample	Design	Instruments	Results/outcome
Anie et al., 2002	Examine relationship between pain, coping, and QOL in adults with SCD, and to assess the influence of these factors on the utilization of health services	96 adults	Cross-sectional design using interview and questionnaire	SF-36, QOL, Coping strategies, Demographic data	Individuals with SCD reported poorer QOL on all eight scales of the SF-36 in comparison with the general population. There were reports of role limitations due to physical and emotional problems, lack of vitality, and poor general health perceptions.
McClish et al., 2005	Assess whether SCD specific variables (genotype, pain, crisis, and utilization) were independently predictive of SF-36 subscales.	308	PISCES study, longitudinal cohort	SF-36-QOL, Demographic data	Patients with SCD experienced health-related QOL that is worse than in the general population and similar to patients undergoing hemodialysis. There is an inverse relationship between pain levels and reports of QOL.
Strickland et al., 2001	Acquire more information on pain persons with SCD experience, coping strategies employed, and impact of disease on QOL	10 with SCD, 11 adult family members living with study participants with SCD	Focus group		Impact of SCD was evident in all major areas of participants' lives. Individuals with SCD were angry and hostile because of perceived negative attitudes of family, friends, and healthcare providers. The perception of others that persons with SCD are drug addicts/drug seeking is emotionally destructive to patients and hampers adequate pain control. Spirituality and religion was used to cope with SCD. Death, anxiety, fatalism, and depression were expressed emotional responses.

Table 1 (continued)

Source	Purpose/ problem	Sample	Design	Instruments	Results/outcome
Thomas & Taylor, 2002	Exploratory study to gain understanding of the psychological impact of SCD, and determine whether these could be conceptualized in terms of QOL as defined by the World Health Organization (WHOQOL).	25	8 non directive focus groups		Participants reported that significant pain, discomfort, and difficulty in controlling pain undermine the physical aspects of QOL. Physical pain depletes the individual's energy level to such an extent that it interferes with rest and activity cycles, and prevents successful completion of everyday tasks.

Measurement of quality of life

The measurement of QOL has been included in many studies in the past; however, the investigator needs to be clear on what is being measured. It is essential to have a clear definition of QOL, assess the dimensions assessed by the instrument, and evaluate the instrument for its relevance to the specific population of interest. Naughton and Shumaker (2003) discuss the importance of selecting an instrument that is appropriate for both the inquiry and the nature of the population. It is recommended to use standardized scales when possible (Naughton & Shumaker, 2003).

Quality of life and health status are distinct constructs, and the two terms should not be used interchangeably. The misnomer and incorrect substitution of these constructs

may result in inadvertent and incorrect use of questionnaires that are designed to measure health status being used for QOL assessment (Smith, Avis, & Assmann, 1999). In validating the difference in the two concepts, Smith, Avis, and Assmann conducted a meta-analysis looking at 12 studies. Quality of life, an end-point in medical care, is important in discussing chronic diseases for which a cure currently is unlikely (Smith et al., 1999). This unlikely cure, despite an individual's optimism, is the situation with SCD. It is imperative for caregivers to focus on correlates of QOL that can be applied to management of individuals with SCD.

There is a discernible difference between QOL, H-RQOL, and health status. Health status refers to functionality within three areas: physical, social, and mental well-being, while H-RQOL and QOL refer to level of satisfaction that an individual derives from life as a "feel good factor" of their health status and subsequent ability to manage everyday life activities (Salek, 1999). Health related quality of life is a multidimensional concept. The existential model of QOL leads to inclusion of such contributors as pleasure in life, and positive outlook to life (Fayers & Machion, 2000). Haas (1999) clarifies the tendency of individuals to confuse QOL definitions with closely related concepts. Quality of life is comprised of four domains that may vary slightly but are generally identified as physical, psychological, social, and spiritual (Haas, 1999a).

Even though QOL relates to health and health status as it impacts QOL, the constructs are different. The World Health Organization's (WHO) definition of health as a "state of complete physical, mental, and social well-being, and not merely absence of disease or infirmity" gives meaning to the limited meaning of health status. In so defining

health status, there is the absence of an individual's ability to determine cognitively and subjectively varying degrees of health-related, personal satisfaction on a continuum of activities that add value to life for the individual who consciously makes that determination. Health status may be subsumed under QOL, but QOL is not health status, and health status is not QOL. Quality of life is based in part on mental outlook, while health status is related to functionality. This study will be focusing on overall QOL as perceived by the individual.

QOL measurements.

Table 2 summarizes measurement tools for QOL among those persons with chronic illnesses. These tools were included because they measure the construct of QOL, and include physical and psychological functioning. The SF-36 has been used in chronic illness QOL studies and among individuals with SCD.

Table 2 Measurement tools for QOL

Instrument	What is measured	Author	Administration	Domains/Scoring
SF-36 Medical Outcomes trust short form	General health across age, disease, & treatment group	Ware & Sherbourne, 1992	5-10 mins Self/interviewer 36 items, 8 distinct concepts	Includes both physical and mental health domains and considers behavioral functioning, perceived well being, social & role disability, and perceptions of health in general. There are eight subsets: physical functioning, role limitations physical, bodily pain, general health perceptions, social functioning, general mental health, role limitations emotional, vitality and general health
SF-12	Abbreviated FS-36	Ware et al., 1996.	5 mins or < Self/interview	Same as above
McGill QOL questionnaire (MQOL)	QOL of individuals with life threatening illness	Cohen, 1995, 1996	16 questions	Single item scale measuring physical well-being and four subscales: physical symptoms, psychological symptoms, existential well-being, and support 4 of 16 questions are related to spirituality, existentialism
Quality of life Index (QLI)	QOL in terms of satisfaction with life, and importance of various aspects of life	Ferrans & Powers, 1985	34 questions, 10 minutes, self-administration	Five scores are calculated: Total QOL score, Health and functioning subscale score, Social and economic subscale score, Psychological/spiritual subscale score, Family subscale score. Four of 34 questions are relevant to spirituality
Functional Assessment of Cancer Therapy- General (FACT-G)	Self perception of QOL. Multidimensional concept of QOL that is subjective and only understood by the individual	Cella et al., 1993	27 items, self-administered in 5 minutes	Overall QOL score and four subscale scores: physical well-being, social/family well-being, emotional well being, and functional well-being

The Medical Outcomes Study 36-Item Short Form (SF-36) is a 36-item generic measure of health status and outcomes relevant across age, disease, and treatment groups. The SF-36, a popular instrument, places emphasis on emotional, physical, and social functioning (Ware, 1993). Ware and Sherbourne (1992) discussed the development, history, and psychometric evaluation of the SF-36 that was designed to survey health status in clinical practice and research by evaluating health related dysfunctions in eight areas of daily activity (Salek, 1999). The measurement includes eight distinct health status concepts and one item measuring self-reported health transition; however, “important health concepts are not represented” and were omitted (Ware & Sherbourne, 1992). The omitted concepts include health distress, family functioning, sexual functioning, cognitive functioning, and sleep disorders. Physical health is divided into scales for physical functioning (10 items), role-physical (4 items), bodily pain (2 items), and general health (5 items). Mental health comprises scales for vitality (4 items), social malfunctioning (2 items), role-emotional (3 items) and mental health (5 items). In addition, there is a general health transition question which asks: “Compared to one year ago, *how would you rate your general health now?*” In addition, there is a global question pertaining to the respondent’s perception of health: “*In general, would you say your health is: (excellent, very good, good, fair, poor)?*” (Fayers & Machion, 2000). The instrument does not provide an overall assessment of QOL (Schlenk et al., 1998). The SF-36 was not selected for this study because the focus of measurement is health status and not QOL.

For the previously mentioned reasons, the brief form, SF-12 was not selected for this study. The SF-12 contains 12 items from the SF-36 Health Survey. The SF-12 was originally developed in 1994 as a shorter alternative to the SF-36. The SF-12 contains one or two measures from the SF-36.

The McGill Quality of Life Questionnaire (MQOL) (Cohen, Mount, Thomas, & Mount, 1996) a single item scale, was designed to measure QOL of individuals with life threatening illness. This QOL scale incorporated the existential domain, balances physical and non physical aspects of QOL, and includes positive and negative influences on QOL (Tarakeshwar et al., 2006). There are 16 items distributed on four subscales: physical, psychological, existential, and support. Six of the 16 items are on the exclusively existential subscale, and “do not represent the relational or transcendent characteristics of spirituality” (Sawatzky, Ratner, Chiu, 2005, p.158). This tool was not chosen as a measurement of QOL in the current study because the spirituality aspect of the tool was unbalanced with items measuring existential spirituality and lacked items measuring faith.

The Quality of Life Index (QLI) (Ferrans & Powers, 1985) was developed to measure QOL in terms of satisfaction with life. The QLI measures both satisfaction and importance regarding various aspects of life. The QLI has as its conceptual basis a combination of several dimensions that include positive mood state, supportive relationships, and the absence of physical and psychological distress. Of the 34 questions of the QLI, four deal with spiritual issues; however, one item asked about religiosity.

The Functional Assessment of Cancer Therapy-General (FACT-G) is the subjective, 27-item core measurement of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system. The FACT-G measures four areas of QOL: physical well-being, social/family well-being, emotional well-being, and functional well-being. This self-assessment questionnaire, although originally developed for individuals with cancer, can be used for any chronic illness such as renal disease, fibromyalgia, Acquired Immune Deficiency Syndrome (AIDS), arthritis, and heart disease (Cella et al., 1993). Some of the studies that have used the FACT-G include Cella, Tulsky, Gray et al. (1993), Webster, Odom, Peterman et al. (1999), Winstead-Fry and Schultz (1997), and Overcash, Extermann, Parr et al. (2001).

The FACT-G is best suited for this study because it measures multidimensional aspects of QOL among individuals with chronic illnesses and has shown high coefficients of reliability and validity. Cronbach's coefficient alpha for the overall scale is .89, with subscales' coefficients ranging from 0.82 to 0.69. The test-retest reliability coefficient at 3 days to 7 days was .92 for the total scale with reliabilities for four subscales ranging from .82 to .88 (Cella et al., 1993; Schultz & Winstead-Fry, 2001). Included in the FACT-G are four distinct, correlated areas of well-being that constitute QOL. These four domains are physical, functional, emotional, and social well-being. The FACT-G offers an overall measurement of QOL and four sub-scale measurements reflective of the four distinct domains. Sickle cell disease, like any chronic illness, affects these four areas of life. The understanding of such impact is best identified subjectively, from the individual's perspective, using the FACT-G.

Spirituality

Overview

Spirituality is difficult to define (Estanek, 2006), but it influences and gives meaning to every aspect of the individual's life (Baker, 2003; Young & Koopsen, 2005). "Spirituality reflects a unique psychological dimension around which individuals organize their lives, goals, values and intentions" (Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, 2003, p.778). Spirituality empowers, and enables individuals to cope and to grow more fully (Frey et al., 2005; Hill & Pargament, 2003), make sense out of their current adverse situations, rise above adversity (Baker, 2003), and find purpose, meaning, and hope (Aldridge, 2005; Brady, Peterman, Fitchett, Mo, & Cella, 1999). Some consider it a quasi-religion. Others view it as a separate entity.

Some have suggested that religion is an institution with varying names and labels, but spirituality is personal and connotes a part of the individual that just is, cannot be extracted or separated, and "lies at the core of one's being" (Narayanasamy, 2002, p.1461). Religion, an important subset of spirituality (King, 2000), reflects an individual's nominal identification with a particular religious denomination, while spirituality is living out one's faith, and focuses on belief, and life's meaning and direction (Baker, 2003; McBrien, 2006). Religious practice is a manner of expressing spirituality, and the two constructs may overlap, but are not the same (Bartlett et al., 2003; Cooper-Effa et al., 2001; Estanek, 2006; Hatch, Burg, Naberhaus, & Hellmich, 1998). Religion and spirituality are contiguous, but not synonymous. As aptly stated by this quote that is attributed to Pierre Teilhard de Chardin,

“We are not human beings having a spiritual journey, but spiritual beings having a human experience” -(Teilhard de Chardin, n.d.).

For the purpose of this study, spirituality is a synthesis of personal, self-expressed beliefs and activities of essence of being that balances and connects other dimensions and domains of human traits and health. Spirituality and spiritual beliefs are interconnected to physical, social, and psychological domains and add balance to human existence.

Focus of essence.

Spirituality, the manifestation of the spirit, provides the essence and meaning of personal interpretation of life events (Laukhuf & Werner, 1998) and creates order of life opportunities (Frey et al., 2005). Essence of being reflects the meaning and purpose in life. Spirituality, then, is the essence of our being that gives meaning and purpose to life (Narayanasamy, 2004). Spirituality, present in all individuals, regardless of religious affiliations, is highlighted when an individual, at a critical juncture, faces emotional stress, physical illness, or death (Narayanasamy, 1999; Narayanasamy, 2002). Spirituality, acting as social support, increases life control (Cooper-Effa et al., 2001), buffers against stress, and facilitates coping. It precipitates changes in an individual’s overall perspective of life and disease impact.

Cooper-Effa et al. (2001) offer concrete suggestions for clinicians who care for individuals with SCD. It is imperative for clinicians to focus more on existential well-being rather than on religiosity and where appropriate, refer individuals for religious counseling. Kristler et al. (1999) noted that all members of the care team must be involved in spiritual care, and consult with clergy or chaplains where appropriate.

Caregivers should also advocate for provision of infrastructure to support the reality of spiritual care.

Spirituality and health

Even though there are many differing camps on the specific impact of spirituality and religiosity and their combined inter-relatedness or separate impact on health and well-being, there is a common thread. The common thread is that spirituality and quasi-religion are important to health. This constant supports the importance of spirituality and caring as the basis of nursing actions (Kristeller, Zumbrun, & Schilling, 1999; McBrien, 2006; van Leeuwen & Cusveller, 2004; Watson, 1985; Watson, 1988). According to Narayanasamy (2002), humans are seen as spiritual beings and there is a connection between spirituality and healing.

Mandated by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), healthcare facilities in the United States are obligated to consider spiritual needs in care delivery. Also, spiritual care of patients is expected of nurses by the nursing code of ethics (ICN [International Council of Nurses], 2000); (ANA [American Nurses Association], 2001). Spirituality is intimately and intricately interlaced in healthcare issues and is fundamental to existence and human survival (McSherry & Draper, 1998).

Both healthcare and spirituality have a commonality in suffering; and both offer deliverance and healing in varying degrees. Healthcare providers (HCP) should be concerned about the individual's spirituality in the context of healthcare provision, healthcare decision-making, reduction of suffering, and enhancement of quality of life

(Young & Koopsen, 2005). Healthcare providers need to open the dialogue halls and practice arenas to incorporate spiritual needs of individuals into practice.

Spirituality and Importance to QOL

It is known that spirituality is an important part of wellness and indispensable in holistic, multidisciplinary, multidimensional care (Hill & Pargament, 2003; O'Connell & Skevington, 2005; Young & Koopsen, 2005). Tuck, McCain and Elswick (2001) refer to Fryback and Reinert who found that spirituality is an “essential contributor to feelings of health and well-being” (p. 777), and spirituality is viewed as a bridge between hopelessness and meaningfulness in the lives of participants with cancer and HIV/AIDS (Tuck, McCain, & Elswick Jr., 2001).

Health-related QOL includes and acknowledges health, illness, and QOL as part of the consumer's healthcare experience. Although spirituality has been regarded as an important element of life, there has been little emphasis on spirituality in medical care, with providers at times avoiding spiritual issues, categorizing it as personal, and attributing little therapeutic value to it (Koenig, George, & Siegler, 1988; Koenig & Larson, 1998). Thus, spirituality has been considered elusive, non-scientific, soft, and personal. There has been, however, documentation of positive impact (Cooper-Effa et al., 2001) and therapeutic value of spirituality.

Spirituality and chronic illness

Little is known about the relationship between spirituality and chronic illness, mostly because of the lumping together of spirituality with religiosity in research studies (Bartlett et al., 2003). However, with more instruments specifically designed for

measurement of spirituality, there should be better studies on the role of spirituality and chronic illnesses.

Landis (1966) evaluated the role of spirituality in individuals coping with chronic illness. Landis studied 94 individuals with diabetes mellitus and found that spirituality (existential well-being) explained 10% of the variance in psychological well-being. The researcher summarized that the findings suggest that “spiritual well being may be an important internal resource for persons forced to adjust to uncertainty related to long term health problems” (p. 217) and chronic illness.

Bartlett, Piedmont, Bilderback, et al. (2003) studied 77 adults with rheumatoid arthritis to evaluate spirituality and its relationship with functional level, psychological well-being, and QOL. The authors concluded that spirituality was associated with happiness and positive health perceptions, and spirituality may increase psychological and physiological resilience in the face of illness.

Two studies on spirituality and SCD are summarized in Table 3. The studies examined spirituality and spirituality/religiosity among persons with SCD. Authors of both studies concluded that spirituality and religiosity contributes to an individual’s coping with SCD.

Cooper-Effa et al. (2001) performed a cross-sectional study of 71 patients with SCD to understand the influence of spirituality on pain experience. The authors concluded that existential well-being is supportive and can help individuals with SCD cope more effectively with the pain of the disease.

Harrison et al. (2005) with a sample of 50 patients examined the role

religiosity/spirituality plays in SCD patients' pain experience. The researchers concluded that individuals who attended church once or more per week reported less pain.

Table 3 Spirituality studies among adults with SCD

Source	Purpose	Sample	Design	Instruments	Results/outcome
Cooper-Effa et al.,2001	The role of spirituality in patients coping with the pain of SCD	71	Descriptive cross-sectional	Spiritual Well-being scale to measure spirituality. West Haven-Yale Multidimensional Pain Inventory to measure ability to cope with pain	Existential well-being was associated with general coping ability with SCD.
Harrison et al., 2005	To examine the role religiosity, spirituality plays in sickle cell patients' pain experience	50	Cross-sectional	700-question assessment tool consisting of demographic information and eight validated instruments. Religiosity was measured with the five-item scale Duke Religious Index	Religious attendance is a predictor of positive health outcomes. Attending church once or more per week is associated with fewer negative experiences with pain and lower levels of psychiatric disturbance for patients with SCD.

Measurement

Spirituality, as a core domain, is not commonly measured in QOL chronic illness studies (O'Connell & Skevington, 2005). Spirituality serendipitously appeared when religion was added, at times as a side-bar issue, or an add-on variable in research studies (Hill & Pargament, 2003). Previous research suggests that spirituality, an important

aspect of QOL (Bartlett et al., 2003), has a health linkage.

O'Connell and Skevington (2005) noted that when authors acknowledged the importance of including measures of spirituality, personal beliefs, and religion in their study design, these measures were typically included in disease-specific measurement tools. Many of the disease-specific tools are not applicable for other population groups. Some studies, although not able to explicitly explain variables, have resulted in data that suggest that just participating in organized religion is enough to make a difference in health outcomes (Baker, 2003). Thus organized religious activities contribute to QOL (Harrison et al., 2005; Koenig et al., 1988; Koenig & Larson, 1998; Weaver & Koenig, 2006). Researchers in developing measures must first define and differentiate between the constructs of religion and spirituality, and then plan to include spirituality in measurement development. Individuals with high symptom load from chronic illness, by using spirituality as a comfort and coping mechanism, can have enhanced well being, improved coping with disease sequela, and an impetus to overcome the burdens of illness (Brady et al., 1999).

There is caution about using tools that may not capture the concept in a generic manner. Stefanek et al. (2005) state that even though the rigor has increased in looking at confounding factors impacting religion/spirituality and H-RQOL among individuals with cancer and life threatening illnesses, there must be a continuation of this trend with the "inclusion of demographic, socio-economic, health status and psychological variables" (p. 459). It is imperative to include such variables because they are risk factors for

disease outcomes, psychological adjustment, and QOL determinants (Stefanek, McDonald, & Hess, 2005).

There has been difficulty in demonstrating, through measurement, the construct of spirituality as personal and singular. Difficulty arises in confounding variables (Frey et al., 2005). Even though there are challenges in isolating spirituality from other domains of QOL measurement, it is imperative for researchers to include this domain because the spiritual domain encompasses important and unique information, with both clinical implications and explanatory power (Brady et al., 1999), and utilizes a holistic approach as posited by Hiatt (1986). Without the inclusion of the spirituality domain in QOL measurement, the information on essence of ‘meaning to life’ is lost.

Spirituality and Research

Since health studies have indicated that spirituality/religiosity is a powerful factor influencing adaptation to illness, it makes sense to desist from the semantic struggle. There should be more research in the spiritual domain. Gained information will ultimately improve clinical practice (Weaver & Koenig, 2006), and practitioners’ understanding of H-RQOL.

Spirituality studies

A number of studies have illustrated health benefits among individuals with both existential spirituality and religious practices. Existential spirituality is not related to a specific denomination, or organized religious practice, but is a perspective whereby the individual seeks purpose, value, meaning in life, and satisfaction (Brady et al., 1999), and

desires a link with the environment and others (Landis, 1966). Studies related to religious/spiritual practices have demonstrated health benefits, but few studies have examined existential spirituality (Matheis, Tulsy, & Matheis, 2006); hence it is often difficult to determine the relationship of QOL to existential spirituality. Discussion of some of the studies that have examined spirituality and QOL will follow.

Matheis, Tulsy, and Matheis (2006), in studying relationships between QOL and spirituality in individuals living with spinal cord injury, reported existential spirituality was the only predictor of QOL, overall health, and life satisfaction, with 98.7% of the entire population reporting engagement in some type of spiritual belief or practice. The authors concluded that “religious spirituality did not emerge as a significant predictor” of QOL (p. 269).

Brady, Peterman et al. (1999), in their quest for validating the importance of including spirituality in QOL studies, concluded that higher levels of spirituality enable endurance of significant levels of symptom load, such as pain, and yet the individual can still enjoy life. Consistent with other studies, Matheis et al. (2006) and Brady et al. (1999) also identified that “compared to Meaning/Peace, Faith evidenced a smaller relationship with QOL” on the FACIT-Sp tool (p. 425). The Meaning/Peace subscale from the FACIT-Sp has more existential spirituality assessments than does the Faith subscale.

Cotton, Levine, Fitzpatrick, et al. (1999) examined the relationships among spirituality, QOL, and psychological adjustment in 142 women with breast cancer. The results of the study revealed a positive correlation between spiritual well-being and QOL. Significant correlations between spiritual well-being and specific psychological

adjustment styles such as a “fighting spirit” were also identified. For this study, the researchers used the FACIT-SP that has two subscales, but only the overall spirituality score was examined, in order to “focus more closely on the relationships among spirituality, QOL, and psychological well-being” (p.432).

There is a spiritual link with health-related issues and QOL. Reicks, Mills, and Henry (2004) concluded from their focus group study that spirituality, internal locus of control, and self-efficacy contributed to weight loss. The participants ultimately felt responsible and exercised internal strength to achieve the desired outcome (Reicks et al., 2004).

Spirituality is associated with happiness and positive health perceptions, thus influencing health over an individual’s lifetime (Bartlett et al., 2003). Brady et al. (1999) found that spiritual well-being remained an important predictor of QOL and enabled endurance of significant symptom load. Cotton et al. (1999) conducted a study with cancer individuals, using the FACIT-Sp and FACT-G, and found that the more ‘spiritually well’ the individual reported, the more likely the individual was to have higher QOL and better psychological adjustment.

Measuring spirituality.

Table 4 includes information about six instruments that measure spirituality. The instruments were selected based on their ability to measure spirituality that includes both religious and existential practices. The focus of the selection of these instruments was on the broad construct of spirituality and not mere religiosity. The ideal instrument must be applicable across religious traditions and varying cultures.

Table 4 Measurements of Spirituality

Instrument	What is measured	Author	Number of questions	Scoring
Spiritual Well Being Scale (SWBS)	Existential and religious well-being	Ellison, C.W., 1983	20	20 items 6-point Likert scale 2 subscales 10 items focus on life satisfaction & life direction (existential well-being) 10 items focus on belief in God (religious well being)
Spiritual Involvement and Beliefs Scale (SIBS)	Spirituality (inclusive, applicable across all religions) Spiritual involvement, activity & beliefs	Hatch, Robert Burg, Mary, Ann, 1998	26	
Spiritual Index of Well-Being Scale (SIWBS)	Designed to measure the effect of spirituality on subjective well-being. There are two components of the measurement: self-efficacy and life scheme	Daaleman & Fry, 2004	12 items, 2 scales	Life scheme measures coping, makes meaning and order of life Self-efficacy

Table 4 (continued)

Instrument	What is measured	Author	Number of questions	Scoring
Systems of Belief Inventory (SBI)	Measures both religious and spiritual aspects of coping with a life threatening illness, as well as its subsequent impact on QOL.	Holland et al., 1998	15 items, 2 scales	One scale with 10 items assesses spiritual and religious beliefs and devotional practices. The second scale with 5 items measures social support obtained from one's religious colleagues and leaders.
43	Sickness Impact Profile (SIP)	Bergner et al., 1981	136 items, 20-30 mins., to complete	2 domains: 12 areas of dysfunction 1. physical :ambulation, mobility, body care, & movement. 2. psychosocial : social interaction, communication, alertness behavior, emotional behavior, sleep/rest, eating, home management, recreation, pastime, employment
Functional Assessment of Chronic Illness Therapy (FACIT-Sp)	Spiritual well-being: meaning/peace and faith	Peterman et al., 2002	12	12 items. Eight items on meaning/peace subscale assess a sense of meaning, peace and purpose in life. Faith, the second subscale, contains four items and measures strength and comfort derived from one's faith.

Paloutzian and Ellison developed the Spiritual Well-Being Scale (SWBS) as a general measure of subjective QOL, and perception of spiritual well-being. The overall spiritual well-being is perceived both as religious well-being and an existential well-being (Boivin, Kirby, Underwood, & Silvas, 1999). The focus of the tool is on God and specific beliefs. Of the 20-item, Likert-type scale, 10 items each contribute to two subscales. One subscale measures life satisfaction, life direction, and existential well-being. The second subscale measures belief in God and religious well-being. This instrument is a good choice for assessing spirituality and was used in Cooper-Effa's 2001 study with SCD.

In another study, using the SWBS, Edmondson, Lawler et al. (2005) investigated the relationship of spirituality to health in a sample of 52 young, healthy adult women. The women were given self-report measurements of spirituality, stress, well-being, and health. The authors found that the existential score (subscale existential well-being) of the SWBS predicted fewer physical health symptoms, and the total spirituality well-being score predicted medication use. There appears to be concomitant health benefits to evidences of high spirituality (Edmondson et al., 2005).

Unfortunately, the SWBS, in measuring religiosity and specific beliefs about God, threatens validity of the broader concept of spirituality (Hatch et al., 1998). Even though this instrument is very popular and has been used in many studies (Hatch et al., 1998), there is limited value of this instrument if used with nonreligious populations because of specific denominational beliefs (Daaleman & Frey, 2004), or among groups with different religious beliefs, for example those of the Buddhist or Muslim faith.

The Spiritual Involvement and Beliefs Scale (SIBS) was developed to be “widely applicable across religious traditions, to assess actions as well as beliefs”, and to address key components that existing measures of spirituality do not address (Hatch et al., 1998, p. 476). The authors discuss the advantage of this instrument in terms of exclusivity and applicability across all religious traditions. The SIBS “assesses spiritual involvement and activity, not just beliefs” (Hatch et al., p. 482).

The SIBS was not selected for this study because of concerns, originally expressed by developers, of test-retest reliability and low Cronbach’s alpha coefficient for factor four- humility/personal application. The low test-retest reliability and low Cronbach’s alpha coefficient “raise concern about validity” (Hatch et al., 1998, p. 483). The authors reported test-retest reliability for factor four as .64 and Cronbach’s alpha as .51. Even though the overall Cronbach’s alpha coefficient is .92, the low reliability of .51 suggests the inability to “capture a homogenous facet of overall spirituality” (Hatch et al., p. 481).

The Spiritual Index of Well-Being (SIWBS) was designed to “measure the effect of spirituality on subjective well-being” (Daaleman & Frey, 2004). The two components of the measurement are self-efficacy and life scheme. Life scheme measures coping, and makes meaning, and order of life events. The second domain (subset) is self-efficacy and depicts the individual’s belief and capacity to arrive at a prescribed goal. The 12-item, two scaled measurement is negatively worded in one direction and predisposes to response bias (Frey et al., 2005). The SIWBS was not chosen for this study because of its psychometric limitation. The one directional, negatively worded items predispose to response bias where

“respondents may answer very quickly without considering the specific wording of items” (Frey et al., p.571).

The Systems of Belief Inventory (SBI-15R) was developed for use in QOL and psychosocial research studying adjustment to illness (Holland et al., 1998). The authors’ purpose for the instrument development was to have a measure that captures “both the religious and spiritual aspects of coping with a life threatening illness as well as the subsequent impact on QOL” (p. 466). The Spiritual Beliefs Inventory (SBI) is a brief 15-item measurement with two subscales. One-subscale with 10 items assesses spiritual and religious beliefs and devotional practices. The second subscale measures social support obtained from one’s religious colleagues and leaders. The SBI measures spirituality and religiosity.

The Sickness Impact Profile (SIP) (Bergner et al., 1981) is a behaviorally based measure of sickness-related dysfunction that was developed for use as an outcome measure for healthcare evaluations (Bowling, 1997; Gilson et al., 1975). It does not measure positive functioning, but “concentrates on assessing the impact of sickness on daily activities and behavior, rather than feelings and clinical reports” (Bowling, 1997, p.40). The aim of the instrument construction was to incorporate both professional and lay perspectives of the impacts of sickness in the context of the Sickness Impact Profile. The measurement includes 12 areas of dysfunction but does not cover global health or QOL (Fayers & Machion, 2000).

The Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp) scale “was designed to be used in health-related research” and is best suited “for

individuals with chronic or life-threatening conditions other than cancer and HIV/AIDS” (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002, p. 57). Even though Daaleman and Frey (2004) have criticized the use of the FACIT-Sp because it is “hampered by inclusion of items that gauge religiosity” (p.502), and contain questions that measure “strength and comfort derived from religious faith,” (p. 502), the instrument is appropriate for this study. Some of the instrument’s items are worded as “my faith or spiritual beliefs” (Peterman et al., 2002, p. 58) and do not exclude individuals from nonreligious groups. Faith by definition is a belief system. The items are general in wording and do not suggest any particular faith.

Peterman et al. (2002) evaluated the reliability of the FACIT-Sp and reported good internal consistency coefficients. The reliability (alpha coefficients) for the total score and two subscales were .81 and .88. Cronbach’s alpha reflects the reliability or degree to which a particular scale measures a single concept. The reliability or internal consistency describes the “average correlation among items within a test” (Nunnally & Bernstein, 1994, p. 251).

The FACIT-Sp was selected for the psychometric properties and the inclusive nature of spirituality over the limitation of religiosity. Studies that have used the FACIT-Sp include Brady, Peterman, Fitchett et al. (1999); Cotton, Levine, Fitzpatrick, et al. (1999) and Peterman, Fitchett, Brady, et al. (2002).

It is then essential to explore spirituality rather than religiosity among individuals with SCD. The proposed study will examine not religiosity, but spirituality and the relationships with QOL and self-efficacy.

Self-efficacy

Self-efficacy as a motivational theory is fundamental to behavior change and represents a response to an attempt to achieve a goal (Bandura, 1997). It is the belief that one can carry out a behavior necessary to reach a desired goal, that is, achieve an expected outcome (Clark & Dodge, 1999) effectively and completely. Self efficacy can predict specific behavior and also results in specific behavior (Bandura, 1997; Clark & Dodge, 1999). According to Bandura's (1977) social cognitive theory, an individual's belief in their ability to overcome specific challenges can propel the individual to overcome obstacles. Encompassed in the individual's belief system are concepts such as mastery, self-esteem, and feelings of being in control of present and future events (Bandura, 1977). Perceived self-efficacy helps to foster coping and response to stress producing events (Bandura, 1982).

It is necessary for individuals with chronic illnesses to change, make adjustments, modify lifestyles, and learn new behaviors. To best manage chronic diseases, individuals must initially and on an on-going basis carry out tasks designed to control symptoms, and avoid acute, as well as chronic, complications (Rapley & Fruin, 1999). Self-care management includes self-talk, mental imaging, and striving for mastery in the areas of intervention. These interventions will enhance the individual's beliefs and confidence in

outcomes. Self efficacy is reciprocally related to performance (Rapley & Fruin, 1999). When efficacy beliefs are enhanced, the individual will strive for increased productivity and higher goal achievement. Hence, self-management, self-care, goal setting, and self-efficacy are all intertwined. The patient who has perceived self-efficacy will be confident, have beliefs in being able to control challenges, and be able to cope and adapt with environmental changes.

Studies of self-efficacy among persons with SCD have been sparse. Self-efficacy influences symptoms and may affect the course and management of chronic illnesses in general (Clark & Dodge, 1999; Edwards et al., 2001; Gillis, 1993), and SCD (Edwards et al., 2001; Edwards et al., 2000) specifically. Table 5 reflects the self-efficacy studies among persons with SCD. The self-report of these individuals is decreased self-efficacy.

In Edwards et al.'s (2001) study, adults with SCD reported lower levels of self-efficacy, more physical and psychological SCD-related symptoms, more pain, and more frequent physician visits compared to those individuals who reported relatively higher levels of self-efficacy. Efficacy beliefs were stable over the one-year study period.

Both Lenoci et al. (2002) and Jenerette (2004) reported similar negative relationships between self-efficacy and healthcare services use. Lenoci et al. (2002) also report a negative relationship between self-efficacy and pain severity.

Table 5 Self-Efficacy studies among adults with SCD

Source	Purpose	Sam ple	Design	Instruments	Results/outcome
Edwards et al., 2001	Investigate the role of self- efficacy in predicting disease symptomatology and health services utilization for adult patients with SCD	147	12 month prospective cohort item	9 item Sickle Cell Self- Efficacy Scale (SCSES)	Perceptions of self-efficacy and disease severity were stable over 12 months. Self- efficacy is an important factor in psychosocial and physical adjustment to chronic illness
Lenoci et al., 2002	Investigate the reliability and validity of the Chronic Illness Assessment Interview for SCD (CIAI-SCD)	104	Descriptive	Rosenberg self-esteem scale, Sickle Cell Disease Self-Efficacy Scale, CIAI-SCD	Individuals with increased scores on the Feeling Concerned and Worried subscale of CIAI-SCD reported more ER visits, increased pain severity, decreased self- efficacy, mastery, and self esteem
Jenerette, 2004	Describe factors that predict QOL in persons with SCD	232	Descriptive design to test Theory of self-care manage- ment	Sickle Cell Self-Efficacy Scale, Descriptive data/ knowledge questionnaire/ vulnerability, Simple Rathus Assertiveness schedule, Family Coping Project Coping scale, Medical Outcomes Study Social Support Survey, Becks Depression Inventory FS, Chronic Illness Quality of Life Scale, Jenerette self-care assessment tool and appraisal of self-care agency	Self-efficacy was significantly negatively correlated with number of complications and number of SCD crises/ year

Measurement

Studies measuring self-efficacy among persons with SCD have used the disease specific instrument Sickle Cell Self-Efficacy Scale (SCSES). This nine-item instrument measures SCD specific perceptions of self-efficacy, and the individual’s ability to function on a day-to-day basis and manage the course of SCD. Table 6 summarizes the SCSES.

Edwards et al., 2000 reported “adequate to good levels of internal consistency” (p. 956) with Cronbach’s alpha of .89. Cronbach’s alpha reflects the reliability or degree to which a particular scale measures a single concept. The reliability or internal consistency describes the “average correlation among items within a test” (Nunnaly & Bernstein, 1994, p. 251). Values of 0.70 and above indicate adequate levels of reliability (Nunnaly & Bernstein).

Table 6 Measurement of Self-Efficacy

	What is measured	Author	Number of Questions	Scoring
Sickle Cell Self-Efficacy Scale (SCSES)	Participants’ perception of their ability to function on a day-to-day basis and to manage SCD symptomatology	Edwards et al., 2000	9	9-item Likert scale Score range 9-45. Higher scores represent greater perceived efficacy for coping with SCD

Summary

This review of the literature explains the concepts set forth in the theoretical framework and supports the need for further study to examine the relationships among QOL, spirituality and self-efficacy in adults with SCD. This is the only known study to examine the three combined concepts among adults with SCD.

Quality of life is a dynamic, individual perspective, comprised of four domains that reflect a balance in human functioning. Hass (1999a) refers to these four domains as physical, psychological, social, and spiritual. In studies of QOL, individuals with SCD reported poor QOL that limited role functioning in physical and emotional areas of life, and affected day-to-day activities. Decrements in vitality and increased pain levels also caused decreased coping, unsuccessful completion of daily tasks, and decreased QOL reports (Anie et al., 2002; McClish et al., 2005; Strickland et al.; 2001; Thomas & Taylor, 2002).

Although the SF-36, a standardized measurement for health status has been used in many QOL studies among individuals with SCD, the FACT-G has been used extensively to measure QOL among individuals with other chronic illnesses. The FACT-G has measured physical, social, emotional, and functional well-being. The FACT-G is best suited for this study because it measures multidimensional aspects of QOL among individuals with chronic illnesses and has shown high coefficients of reliability and validity. The overall score of QOL and subset scores on each of four dimensions are valid indicators of QOL for those with chronic illness.

Spirituality as a core domain has not been included in many chronic illness studies pertaining to QOL and self-efficacy. Instead, many chronic illness studies have included religiosity. Measuring religiosity instead of spirituality results in failure to include diverse religious and cultural populations (Brady et al., 1999; Peterman et al., 2002), and threatens validity.

Spiritual concerns and conflicts often accompany chronic illnesses, but may not be addressed under the guise of a biomedical model (Aldridge, 1991; Borrell-Carrió, 2004; Brody, Cardinal, & Foglio, 2004; Hiatt, 1986). Hiatt (1986) refers to spirituality (spiritual dimension) as an area that has received little attention compared to the other aspects of personhood. Furthermore, like physical or psychological development, spiritual development is lifelong, and follows an uneven, stepwise course with the intent of unifying all aspects of life (Hiatt, 1986). Spirituality then in the presence of suffering may help the individual find purpose, meaning, hope (Aldridge, 1991; Hiatt, 1986), and empowerment (Frey et al., 2005; Hill & Pargament, 2003) to overcome the adversity of chronic illness.

Spirituality, a part of all humans, is a necessary element of life and health, and an important connector or bridge between health and illness (Narayanasamy, 2002; Tuck et al., 2001; Watson, 1985). Recently, there has been more inquiry into the impact spirituality has on health and the management of chronic illness. Generally, there is agreement that spirituality improves psychological and physiological adaptation to illness (Bartlett et al., 2003; Landis, 1966). There, however, have not been many studies on spirituality and persons living with SCD. The conclusion of Cooper-Effa et al.'s 2001

study reflected that existential well-being helped individuals with SCD cope more effectively with disease-associated pain.

Studies should measure existential spirituality and not religiosity. Measuring religiosity and specific beliefs about God threatens validity of the broader concept of spirituality (Hatch et al., 1998). The FACIT-Sp is well suited for this study because of its psychometric properties and the inclusive nature of spirituality over the limitation of religiosity.

Self-efficacy helps to foster coping and response to stress-producing situations (Bandura, 1982) such as chronic illness. For chronic illness management, the individual must institute self-care management skills to foster goal achievement. There have been few studies on self-efficacy among adults with SCD. The consensus of these studies is that self-efficacy is important to psychosocial and physical adjustment to chronic illness. The studies that have measured self-efficacy among adults with SCD have used the disease specific instrument, SCSES. Individuals who responded with higher scores perceived more efficacy for coping with SCD.

CHAPTER 3

METHODOLOGY

Research design and Methods

The purpose of this study was to describe and explore relationships among quality of life (QOL), spirituality, and self-efficacy in adults with sickle cell disease (SCD). There remain many unanswered questions regarding spirituality, QOL, and self-efficacy. Described in this chapter are the research design, population and sample, instruments, procedures, and data management approaches.

Research Design

This study used a descriptive correlational design to describe and examine the relationships among spirituality, self-efficacy, and perceived QOL in adults with SCD. Mail out and electronic mail survey methods were used for data collection. Data were collected from a sample of convenience.

Sample.

To be included in the study, participants had to have SCD, be at least 18 years old, and able to read and write English. Those with sickle cell trait were excluded from the study.

Sample size was determined by power analysis using Lenth's (2006)

computer software. Using a small effect size of 0.3, alpha set at 0.05, and power of .80, the desired sample size for this study was calculated as 64 participants.

Study participants were recruited through various venues including local chapters of the Sickle Cell Disease Association (SCDA) and a personal e-mail list provided by a member of the national SCDA. The sampling method included both mail-out and electronic web based surveys. The study was planned to use mail-out surveys but because of initial low response rate, the data collection package was converted to an on-line survey using *Survey Monkey*.

Prospective participants with Sickle Cell Disease, who receive services from the Sickle Cell Disease Association, Dallas (SCDAD) were invited to participate in the study via US postal service mail outs. The SCDAD is a community based not-for-profit organization that offers services that focus on improving the quality of life and empowerment of individuals, and families of those affected by sickle cell disease. Services offered include case management, public outreach, sickle cell screening and testing, and genetic counseling. Staff social workers and case managers provide psychosocial services. There were approximately 120 individuals in the mailing list database. In addition to the US postal service mail outs, an electronic medium was used.

An invitation to participate in the electronic survey was e-mailed to persons with SCD who were included in the distribution list of an individual associated with the national SCDA. The member of the national SCDA contacted individuals from her personal mailing list and informed them of the *Survey Monkey* website. The script on the

survey site was the same script as that sent via US postal service mail. The protocol for the electronically offered survey was the same as the mail out survey.

The third source of subjects was persons with SCD and without computers who were identified by SCDA center directors. After *Survey Monkey* was launched, Directors of two SCDA chapters (SCDA-Alabama and SCDA-North Carolina) requested mailed versions in lieu of the electronic format. The Directors affixed mailing labels to the completed packets and mailed them to prospective participants, keeping potential subjects' identities confidential.

Table 7 shows the response rate for each recruitment source. Two hundred survey invitations to participate were mailed. Seventy-three were returned, with a response rate of 36%. One survey was discarded because the participant recorded sickle cell trait as the type of disease. In addition to the mailed responses, there were 18 responses from *Survey Monkey*. The total number of participants for this study was 90.

Table 7 Mailed Surveys, response rate, and electronic survey response

Mailed Source	Invitation Extended	Returned Number of Completed Surveys	Mailed Response Rate	Survey Monkey Completed	Total study Participants
SCDAD et al.	119	36*	29.4%		
SCDA (Alabama)	55	31	56.4%		
SCDA (North Carolina)	26	6	23.1%		
Electronic Survey				18	
Total	200	72	36%	18	90

* The data of one survey respondent with sickle cell trait were discarded

Measurement Methods

Instruments

A battery of psychometrically sound instruments designed to examine the constructs QOL, spirituality, and self-efficacy were selected for this study (see Table 8). A demographic survey developed by the researcher was used to collect data on sample characteristics. The entire survey, including demographic information, consisted of 57 items. The Functional Assessment of Cancer Therapy-General (FACT-G) was used to measure QOL. The Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp) measured spirituality, and the SCSES (Sickle Cell Self-efficacy Scale)

measured self-efficacy. All tools were used according to guidelines from the developers.

None of the tools were changed or modified. Examples of each measure appear in

Appendix A.

Table 8 Description of variables, definition and measurement

Variable	Conceptual Definition	Operational Definition and Measurement
Quality of life	Quality of life is the individual's expressed interpretation of life events, and self-perception of well-being.	Using Functional Assessment of Cancer Therapy (FACT-G) (Cella et al., 1993), participants were asked to rate abilities or feelings about QOL experienced within the last seven days.
Self-efficacy	Self-efficacy is the belief in one's capabilities to enable and execute a course of action for a required task by rating his/her ability to complete tasks pertaining to day to day symptom and disease management.	Using Sickle Cell Self-Efficacy Scale (SCSES) (Edwards et al., 2001), participants were asked to rate their ability to complete tasks pertaining to day to day symptom and disease management.
Spirituality	Spirituality is a synthesis of personal, self-expressed beliefs and activities of essence of being that balances and connects other dimensions and domains of human traits and health.	Using Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp), (Peterman et al., 2003), participants were asked to rate feelings and thoughts about spirituality experienced within the last seven days.

Functional Assessment of Cancer Therapy-General (FACT-G).

The Functional Assessment of Chronic Illness Therapy (FACIT) measurement system was developed over 10 years, from 1987 to 1997, to measure QOL among those with chronic illnesses and cancer. The FACIT system includes the Functional Assessment of Cancer Therapy-General (FACT-G) and the Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp). The FACIT measurements have been used in multilingual and multicultural populations with cancer and chronic illnesses (Bonomi et al., 1996). According to the website information, as of 2003, there are over 40 different FACIT scales, with equivalent foreign language versions in more than 45 different languages. This wealth of FACIT measurements has permitted “cross-cultural comparisons of people of diverse backgrounds” (Functional Assessment of Chronic Illness Therapy (FACIT) measurements, 2007). Version 4 of the FACT-G was developed in 1997 (Lent, 1999). The FACT-G measurements have not been used in any study of individuals with SCD.

The FACT-G is the core component for instruments originally developed for QOL assessment, and can be completed in five minutes (Cella et al., 1993, p. 575). The FACT-G version 4 is a self-assessment 27-item core measurement of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement system. This self-assessment questionnaire, although originally developed for individuals with cancer, can be used for any chronic illness, such as renal disease, fibromyalgia, Acquired Immune Deficiency Syndrome (AIDS), arthritis, and heart disease (Cella et al., 1993).

The conceptual framework for the FACT-G is based on Cella et al.'s (1993, 1994) views on QOL as a multidimensional concept that is subjective and only understood from the patient's perspective. Quality of life cannot be measured by the patient's behavior or by observing the patient. Quality of life is the individual's value or appraisal of satisfaction with current level of functioning compared to perceived ideal or benchmark. Quality best understood of life encompasses multidimensional health and is as the individual's representation of the gap between one's actual functioning level and one's ideal standard (Cella, 1994, p.187).

In terms of the multidimensionality of QOL, there are four distinct correlated areas: physical, functional, emotional and social well-being. Discussions of these four domains follow. The *physical well-being* refers to perceived and actual body function or disturbances, such as pain or fatigue, and any disease or treatment related discomfort. *Functional well-being*, which is different from physical well-being, includes the individual's ability to perform activities pertaining to social role, personal needs, ambitions, activities of daily living, and execution of responsibilities inside and outside the home (p. 188). Albeit the physical and functional dimensions are closely linked to one another, they can be independent and may be reflected when an individual is able to continue working effectively despite pain (Cella, 1994). The physical and functional domains are separate but impinge on the *emotional well-being*. The emotional well-being is "bi-polar" (p.188), and reflective of a position on a continuum between positive perception of well-being and negative perception of distress. The emotional state reflects one's ability to cope with stress and the burden of disease. A comprehensive health-

related evaluation will help to determine one's fulcrum or balancing point on this bipolar dimension. The *social well-being* includes "maintenance of gratifying relationships with friends and acquaintances and intimate relationships with family members and significant others" (p. 188-189). Development of some of these relationships fosters patient coping and adaptation to illness and is reflective as integrative parts of the whole well-being (Cella, 1994). These four dimensions interlock, impinge on each other, and reflect the multidimensionality that can best be explained or rated by the patient.

The FACT-G was validated in five phases, over 10 years, beginning in 1987 until 1997. Version 4 was produced in 1997. Cella et al. (1993) reported validity assessment in a population of 845 patients with cancer at different stages. Convergent validity was demonstrated with a .79 Pearson product moment correlation when compared with the Functional Living Index Cancer (FLIC), a similar QOL scale used for cancer patients.

The FACT-G has demonstrated high coefficients of reliability and validity. Cronbach's coefficient alpha for the overall scale is .89, with subscales coefficients ranging from .82 to .69. The test-retest reliability coefficient within 3 to 7 days was .92 for the total scale. Reliabilities for four subscales ranged from .82 to .88 (Cella et al., 1993; Schultz & Winstead-Fry, 2001).

The FACT-G measures four areas of QOL: physical well-being, social/family well-being, emotional well-being, and functional well-being. The physical well-being (PWB) scale includes items GP1 to GP7, with scores ranging from 0-28. The social/family well-being (SWB) subscale includes items GS1 to GS7, with scores 0-28. The emotional well-being (EWB) subscale has score range 0-24, and reflects items GE1

to GE6. The functional well-being (FWB) subscale is represented by GF1 to GF7, with score ranges from 0-28. The responses on each scale range from *not at all (0)*, *a little bit (1)*, *somewhat (2)*, *quite a bit (3)*, to *very much (4)*. Respondents are directed to recall experiences for the past seven days and respond accordingly.

The FACT-G can be scored as a total score to reflect a summary of the overall QOL, or each individual subscale can be scored. The total score for FACT-G is 0-108, with 0 representing the worst QOL, and 108 representing the best QOL. The scores for both the total score and for the sub-scales can be computed if more than 50% of the items in the category are present. With more than 50% of items present, a prorated subscale score is acquired based on the formula outlined in the FACIT manual. As directed by the manual, some items are reversed before a score is computed. The sum of the item scores is multiplied by the number of items in the subscale and then divided by the number of items answered. This produces the subscale score. All the subscale scores are added to acquire the total FACT-G score.

Functional Assessment of Chronic Illness Therapy Spiritual (FACIT-Sp).

The Functional Assessment of Chronic Illness Therapy Spiritual (FACIT-Sp) is part of the larger FACIT measurement system. The FACIT-Sp is a 12-item spirituality measure and focuses on the existential aspect of spirituality and faith and assesses this on two subscales: meaning/peace and faith. Items cover issues such as having a reason to live, finding purpose or meaning in one's life, finding strength or comfort in one's faith, and the effect the illness has on one's faith.

The conceptual framework for the development of FACT-Sp is based on the importance of studying the relation between spirituality, interconnectedness of mind, body and spirit, and the demographic change from organized worship and religion to a personal search for spiritual fulfillment (Peterman et al., 2002). The FACIT-Sp was “designed to provide an inclusive measure of spirituality that could be employed in research with people with chronic and/or life-threatening illnesses ” (Peterman, 2002, p.50). Also of consideration is the importance of examining spirituality as a concept rather than religiosity. Examining religiosity alone would exclude many who do not subscribe to denominational or specific religious beliefs yet have spiritual beliefs and practices (Peterman et al., 2002). Cotton et al. (1999) point out that the FACIT-Sp measures internally-based constructs such as meaning, purpose and strength, and these constructs are important and may influence a patient’s QOL (Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999). The FACIT-Sp also is void of religious symbolism or attributes.

The FACIT-Sp was developed with the input of cancer patients, psychotherapists, and religious/spiritual experts who were asked to describe the aspects of spirituality and or faith that contributed to QOL. The FACIT-Sp was validated in two phases. The first study of the FACIT-Sp was done “to establish the factor structure, reliability and initial validity of the instrument” (Peterman et al., 2002, p. 50). Data were collected in conjunction with a large scale validation of the FACIT measurement system across languages and cultures. The languages were Spanish vs. English, and cultures were Hispanic vs. White non-Hispanic vs. Black non-Hispanic. The original sample contained 1,617 subjects who were diagnosed with cancer or HIV infection/AIDS. The subjects

were asked to describe aspects of spirituality and/or faith that contributed to QOL. The FACIT-Sp scale and subscale reflected good reliability with alpha coefficients .81 to .88. The authors reported “moderate to strong correlations between the total FACIT-Sp and QOL”, as measured by the total FACT-G and subscale scores (Peterman et al., p.52).

Having established the reliability of the FACIT-Sp and a significant relationship between spiritual well being and QOL in patients with chronic diseases, a second study was done. The second study was done to validate the FACIT-Sp by examining its relationship to existing measures of religion and spirituality (Peterman et al., 2002). Study 2 was part of a larger study, looking at fatigue and QOL, with 131 individuals who were receiving outpatient chemotherapy. The participants completed five measures of religion/spirituality. The comparison of the FACIT-Sp with the other religion/spirituality measures helped to establish convergent validity of the FACIT-Sp, as well as documented the degree to which the FACIT-Sp appears to measure items not reflected by other existing scales (Peterman et al., 2002). The FACIT-Sp assesses spirituality across a range of religions, traditions, and cultures. The items in the scale do not refer to specific religious beliefs, denominations, or practices; hence, the instrument reflects inclusive spirituality.

There are 12 items to this scale. The statements pertaining to response to illness within the past seven days are ranked by responses that range from *not at all (0)*, *a little bit (1)*, *somewhat (2)*, *quite a bit (3)*, to *very much (4)*. The range of scores is 0-48, with 48 representing high level of spirituality. As described in the manual, missing data from subscales are prorated by multiplying the sum of subscale by number of items in the

subscale, and then dividing by the number of items actually answered (Functional Assessment of Chronic Illness Therapy packet). The FACIT-Sp has sound psychometric properties, including concurrent and construct validity, and Cronbach's alpha from .81 to 0.88. The FACIT-Sp is scored under the same conditions as described with the FACT-G. The scores for the total score as well as for the sub-scales are computed if more than 50% of the items in the category are present. With more than 50% of items present, a prorated subscale score is acquired based on the formula outlined in the FACIT manual. Some items are reversed before a score is computed. The sum of the item scores is multiplied by the number of items in the subscale, and then divided by the number of items answered. This produces the subscale. All the subscale scores are added to acquire the total FACIT-Sp score.

Sickle Cell Self-Efficacy Scale (SCSES).

The Sickle Cell Self-Efficacy Scale (SCSES) is a 9-item instrument that measures SCD specific perceptions of self-efficacy, the individual's ability to function on a day-to-day basis and to manage SCD symptomatology. The instrument was investigated in a community-based sample of adults with SCD. The SCSES provides an overall index of self-efficacy by totaling item scores; higher scores indicate greater self-efficacy (Edwards et al., 2001).

The theoretical framework on which this instrument is based is self-efficacy, a component of Bandura's (1977) social learning theory. The social learning theory refers to an individual's judgment of his or her capacity to perform specified tasks which results in specific outcomes (Edwards et al. 2000). Self-efficacy acts as a predictor of adjustment

to illness and reflects positive measures of self-esteem, mastery, and internal locus of control (Edwards et al., 2000).

The SCSES initially was tested on 83 adult, community-based participants with SCD, genotype HbSS (Edwards et al., 2000). Another longitudinal study with one year follow-up of 147 participants concluded that self-efficacy beliefs among African Americans with SCD are inversely related to reported disease symptomatology (Edwards et al., 2001). Although self-efficacy has been measured in other studies with African Americans with SCD, a disease specific assessment measure such as the SCSES was not used.

The SCSES authors reported Cronbach's alpha as .89 (Edwards et al., 2000). Convergent and predictive validity were assessed with three sets of analyses in which the relationships of SCSES scores to related constructs, SCD symptoms, and healthcare utilization were examined. The interrelationships among self-esteem, sense of mastery, internal health locus, and SCSES scores were done first. There was statistical significance at 0.01 level. Greater SCSES total and subscale scores were associated with increased self-esteem, mastery, and internal health locus of control. Predictive value was determined by computing correlations between SCSES scores, total SCD physical symptoms, and sickle cell pain occurring in the previous 30 days. These variables were negatively related, suggesting higher self-efficacy is associated with decreased pain reports and lower levels of reported physical symptoms (Edwards et. al, 2000).

The response categories for each item range from "not at all sure" to "very sure." Scoring of the SCSES is done by totaling all answers, with a possible highest score of 45

and a possible low of 9. Higher scores reflected greater self-efficacy. The authors state that it takes 2 minutes to complete the questionnaire, but they did not discuss the procedure for handling missing data. Missing data with this instrument will be handled in the same manner as described for the FACIT and FACT-Sp.

Reliability of instruments

Internal consistency estimates of reliability were computed for the FACIT-Sp, FACT-G and SCSES scales. The appropriate items, as directed by the authors' manuals were reverse-scaled prior to scoring. Values for coefficient alpha (Cronbach's alpha) were .86, .93, and .81 respectively, each indicating satisfactory reliability. The coefficient alphas equal to or greater than .79 suggest that the scale scores are reasonably reliable for those respondents in this study. Table 9 shows the comparison of reported reliabilities from authors of measures with reliabilities of measures for this study. The coefficient alpha reliabilities of this study for spirituality, QOL and self-efficacy were .91, .93, and .87 respectively.

Table 9 Comparison of literature reported reliabilities and reliabilities of this study

Scale	Reliability reported in the literature by authors of measurement	Cronbach's alpha Reliability for this sample
Quality of life (FACT-G)	.89	.93
Physical well-being	.82	.88
Social/family well-being	.69	.84
Emotional well-being	.74	.82
Functional well-being	.80	.89
Spirituality (FACIT-Sp)	.87	.91
Meaning/Peace	.81	.88
Faith	.88	.86
Sickle cell self-efficacy (SCSES)	.89	.87

Demographic data

The demographic data sheet included in the research packet (Appendix A) includes basic descriptive information such as educational level, age, income, and use of hospital services. Four focused questions pertaining to QOL, disease presentation, and utilization of healthcare services germane to individuals with SCD and suggested by

literature review and testimonials were also included with the questionnaire. This section took about 2 minutes to complete. Prior to its use in this study, sample questionnaires were given to adults with knowledge of sickle cell disease, and all completed the questionnaire in less than two minutes.

Procedure

This descriptive correlational study was conducted using both mail-out and electronic web-based surveys. The study was planned to use mail-out surveys but because of low response rate, the data collection package was converted to an on-line survey using *Survey Monkey*.

The mail-out surveys invited prospective participants from a SCD database to participate. For the mail-out survey, an introductory letter from the CEO of the SCDAD, and an invitation letter from the investigator accompanied each participant's packet. The mail out packet included the invitations, study guidelines, inclusion criteria, demographic assessment, and study questionnaires (see Appendix A).

Similarly, individuals from a personal electronic distribution list were invited to participate. For the electronic survey, the same protocol was used. A member of the national SCDA contacted individuals from her personal, electronic distribution list and informed them of the link to the survey. The electronic packet information appears in Appendix F. Fliers informing prospective participants of the study and website were also posted in areas frequently visited or used by individuals living with SCD. Some of these areas included: emergency rooms, hospital clinics, hair salons, barbershops, and specialty food stores. The information on the flier appears in Appendix G.

Each instrument was created in teleform. Each mailed packet included a stamped self-addressed envelope for return of completed forms. Prospective participants were assured that research findings would be made available at the end of the study. Participants were informed that they could contact the collaborators from the SCDAD and the individual from the national SCDA for results after approximately six months. The electronic version of the survey was created using *Survey Monkey* and was available to any prospective participant who visited the website. The script was the same for both types of surveys.

Sealed mail packets with stamped self-addressed envelopes for return of completed forms were sent to Directors of SCDA chapters who requested the mailed version in lieu of the electronic format. The Directors affixed mailing labels to the completed packets and mailed to prospective participants.

In order to protect patient anonymity and prevent inclusion of any identifying information, the packets were prepared and sealed by the investigator, who affixed stamps and mailing labels acquired from the SCDAD. To minimize low response rate, there was a follow-up with postcards mailed out on day seven and day fourteen after the initial packet mail out. The postcard reminders are in Appendix D. For the electronic survey, the owner of the distribution list sent e-mails at days seven and 14 to remind persons on the list to complete the survey.

The participants returned completed surveys to the principal investigator in a provided stamped, addressed envelope. The prospective participants were encouraged to return the completed survey within seven days of receipt. Completion and return of the

mailed survey served as consent to the research process. The electronic surveys were returned electronically.

Ethical Considerations

The project was approved by the University of Texas at Arlington Institutional Review Board (IRB) for protection of human subjects prior to implementation. The IRB approved the various venues of subject recruitment.

All responses were kept confidential and were only viewed by the investigator conducting the study. Code numbers were assigned to each participant's teleform. The investigator was not able to link any responses to specific participants. All research data were stored under double lock and key. The risk/benefit for this study was explained to prospective participants in the invitational letter.

Compensation of \$10.00 was offered to all participants. The participants who wished to receive the compensation completed a white envelope with their name and mailing address and returned it with the completed survey. For the electronic survey, participants who wished to receive compensation for participation included their name and mailing address at the end of the electronic survey.

Data Analyses

Upon receipt of a data package from a subject, forms were checked for completeness. Missing data were identified. Non-study materials were separated from study materials. All data forms were scanned electronically into an SPSS data file, and

the data file was checked for accuracy using both the software provided checks and by physical examination of randomly selected data points. Missing data were handled as consistent for all scales and as described in the FACIT scoring manual. However, prorating of scale and subscale scores was not required as there were only four missing items from any one respondent. With greater than 50% of items answered, prorating was unnecessary. Using the published scoring guidelines, a total score and sub-scales scores were completed for each measure. The FACIT-Sp has a total and two subscale scores. The FACT-G has a score total and four subscale scores. The SCSES has a score total.

Data were analyzed using Statistical Package and Service Solutions computer program (SPSS 14.0 for Windows, 2006). The alpha that was used to determine the statistical significance was $p < .05$. Two assumptions underlie the use of Pearson's product moment correlation coefficient as a statistical technique. The first assumption is that variables are bivariately normally distributed. That is, each variable is normally distributed ignoring the other variable and each variable is normally distributed at all levels of the other variable. With the bivariate normality assumption the relationship between two variables is linear. The second assumption is that there is independence of scores on one variable from scores of other variables (Green & Salkind, 2005). The bivariate normality assumption was met and a linear relationship existed between two and more variables. The linear relationship was assessed visually by examining a scatterplot of the data points. The independence assumption was met in this study.

Frequencies and descriptive statistics were used to describe the demographic characteristics of the sample and the three variables: QOL, self-efficacy and spirituality.

The research questions were answered using Pearson product-moment correlation coefficient and a general linear model with multifactorial analysis of variance (ANOVA). The general linear model with ANOVA was used to “assess the simultaneous effects of two or more independent variables (factors) on a dependent variable” (Corston & Colman, 2003, p.84). The assumptions of the ANOVA are: 1) the dependent variable is normally distributed for each of the population as defined by levels of the factor, 2) variances of the dependent variable are the same for all populations (homogeneity of variance), and 3) scores are statistically independent of each other.

Delimitations:

1. The sample was not randomly assigned, but a convenience sample of those who volunteered was used. The convenient sample affected generalizability because of possible lack of representativeness of the general population.
2. To receive compensation for completing the questionnaire participants had to self identify. Some participants may not have volunteered participation because of not wanting their responses to be linked to compensation. Participants who did not want their privacy invaded could choose not to self-identify and not to request compensation.
3. Financial need of the offered compensation (\$10.00) may have been tempting to some participants.
4. Getting participants from an indirect source may have also limited participation. Participants were introduced to the research project by mail invitation (US mail and

electronic mail), and via flyers posted in places frequented by those with ethnic make-up that is highly suggestive of SCD. This may have excluded some who do not fit into the ethnic makeup mold.

Summary

A descriptive correlational design was utilized to describe and examine the relationship among spirituality, self-efficacy, and QOL in a sample of adults with SCD. A sample of n = 90 adults with SCD were recruited to respond to questions about spirituality, self-efficacy, quality of life and demographics. Appropriate IRB approval was obtained and subjects were recruited from various venues. The venues included chapters of the Sickle Cell Disease Association (SCDA), invitation fliers posted in service areas frequently visited by individuals with SCD, and through a personal electronic distribution list of an individual associated with the national SCDA. The mechanisms of recruitment from these venues included using US postal service mail outs and electronic surveys.

The data was analyzed using Statistical Package and Service Solutions (SPSS 14.0 for Windows, 2006). The research questions were answered using Pearson product-moment correlation coefficient and a general linear model with multifactorial ANOVA. The results of data analysis will be useful in planning interventions in the areas of spirituality, self-efficacy, and QOL in other populations in addition to those with SCD

CHAPTER 4

FINDINGS, RESULTS, DISCUSSION

Introduction

The primary objective of the study was to explore and describe the relationships among spirituality, self-efficacy and QOL in adults with SCD. Data about the relationships among spirituality, self-efficacy, and QOL in adults with sickle cell disease (SCD) were collected from 90 subjects. Each provided information about their SCD genotype, country of birth, age, gender, educational level, household income, and number of hospitalizations within the last year. The results were analyzed using Statistical Package and Service Solutions computer program (SPSS 14.0 for Windows, 2006).

Results

Description of the Sample

The convenience sample of this study consisted of persons with SCD who were at least 18 years old and able to read and write English. The 90 participants completed a US postal mail out or an electronic survey. Demographic information with frequencies and percentages for the sample is presented in Table 10. Participants' ages ranged from 18 to 67 with a mean age of 39.48 years. The majority (74.4%, n=67) were females. As shown in Table 10, most respondents were single and relatively well educated. Most respondents

(75%) had education beyond high school. Despite being well educated, these participants had quite low annual household income. More than half of the respondents reported annual incomes of less than \$20,000. Table 10 also shows the percentage of respondents with each SCD genotype. All who reported having Sickle Beta Thalassemia were females. One female also reported having another genotype, SC Harlem. Most of the respondents reported being admitted to the hospital one to two times in the previous year (mean 2.58, *SD* 2.71).

The United States was the country of birth for 84.9% (n=79). Other countries that were reported were Costa Rica, Haiti, Jamaica, Liberia, Nigeria, Trinidad, and Zambia. The other countries that were reported reflect 13% (n = 11) of this sample.

This sample was similar to persons with SCD reported in other studies in the areas of income, gender proportion, genotype, and level of educational attainment. In this study of the 90 participants, there were more females than males with 74% being females and 26% males. Jenerette (2004) studied 232 and reported a similar distribution. In Jenerett's study, 60% were females and 31% were males. In the Healthcare Cost and Utilization Project (HCUP) report (2006), females were 53% and males were 47% of their sample. Lenoci, Telfair, Cecil and Edwards (2004) reported their sample had 44% females and 33% males. In the current study 52% of the participants were single. In Lenoci et al.'s 2004 study 58% of the sample were single.

Genotype presentation "is the most important risk factor for disease severity" (Ashley-Koch et al., p. 842, 2000). Individuals with Hemoglobin SS (HbSS) are more severely affected than those with Hemoglobin SC (HbSC). Lenoci et al. (2004) reported

on genetic information for the clientele at the study center being comprised of individuals of whom 51% have HbSS form of SCD, 33% have hemoglobin SC(HbSC) , and 16% have hemoglobin beta-thalassemia. In this study, the genotypic distribution was 51.2% (n=44), HbSS, 31% (n = 29) HbSC, and 15.1% (n=13) hemoglobin beta- Thalassemia.

The reported income in this study showed that 66% of the participants earned less than \$35,000. The HCUP (2006) report showed that 55% of the respondents earned less than \$36,000 per year. In Jenerette's (2004) study the educational level was reported as mostly beyond 12th grade. In this research study, more than 75% reported having some college. This is a highly educated group for persons with chronic illness.

Table 10 Demographic Characteristics (N = 90)

Characteristics	Total % N = 90	Female % N = 67	Male % N = 23
Marital status			
Single	51.6%	34 (50.7%)	14 (60.9%)
Married	23.7%	16 (23.9%)	6 (26.1%)
Divorced	16.1%	14 (20.9%)	1 (4.3%)
Separated	1.1%	1 (1.5%)	
Widowed	2.2%	1 (1.5%)	1 (4.3%)
Other	2.2%	1 (1.5%)	1 (4.3%)
Educational level			
Less than high school	6.5%	3 (4.5%)	3 (13%)
High school diploma/GED	15.1%	11 (16.4%)	3 (13%)
Some college	48.4%	36 (53.7%)	9 (39.1%)
Bachelor's degree	19.4%	12 (17.9%)	6 (26.1%)
Graduate degree	7.5%	1 (7.5%)	2 (8.7%)
Annual household income			
Less than \$10,000	32.3%	23 (34.3%)	7 (30.4%)
\$10,000-\$19,000	23.7%	15 (22.4%)	7 (30.4%)
\$20,000-\$34,000	9.7%	7 (10.4%)	2 (8.7%)
\$35,000- \$49,000	9.7%	6 (9%)	3 (13%)
\$50,000- \$60,000	7.5%	6 (9%)	1 (4.3%)
More than \$60,000	14%	10 (14.9%)	3 (13%)
Sickle cell disease genotype			
HbSS	47.3%	32 (42.9%)	12 (52.2%)
HbSC	31.2%	20 (30.8%)	9 (42.9%)
Sickle Beta Thalassemia	14%	13 (20%)	
Other	1.1%	1 (1.1%)	
Missing			2

Table 10 (continued)

Characteristics	Total % N = 90	Female % N = 67	Male % N = 23
Hospitalization in previous year			
0	20.4%	15 (22.4%)	4 (17.4%)
1	21.5%	14 (20.9%)	6 (26.1%)
2	21.5%	16 (23.9%)	4 (17.4%)
3	8.6%	3 (4.5%)	5 (21.7%)
4	6.5%	6 (9%)	
5	5.4%	3 (4.5%)	2 (8.7%)
6	4.3%	3 (4.5%)	1 (4.3%)
7	1.1%	1 (1.5%)	
8	1.1%	1 (1.5%)	
9			
10	6.5%	5 (7.5%)	1 (4.3%)
Hospitalization based on genotype			
HbSS	51.2%	32 (49.2%)	12 (57.1%)
HbSC	33.7%	20 (30.8%)	9 (42.3%)
Sickle Beta Thalassemia	15.1%	13 (20%)	

Blank spaces indicate data not applicable

Aims

Aim one. Relationships among Spirituality, Self-efficacy and Quality of Life

Table 11 represents descriptive statistics for study variables. Quality of life was measured with the Functional Assessment of Cancer Therapy (FACT-G). The average score was 72.3 (SD 20.1). With SD of 20.1, there is a wide variability in responses.

Cronbach's alpha for this study was .93. From literature review, the FACT-G has not been used before with individuals with SCD. It has been extensively used with individuals with cancer and other chronic illnesses. Brady et al. (1999) reported the FACT-G reliabilities of .72 to .85 for the subscales. No total score reliability was reported. Tate and Forchheimer (2002) in their five stratified diagnostic groups study measured QOL using FACT-G. The authors reported a mean total FACT G score of 89.4 (*SD* 15) for individuals with breast cancer, but did not report reliabilities for the total score or subsets. In this study, for the average person QOL was moderate (*M* 72.3, *SD* 20.1)

Spirituality was measured with the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp with higher scores indicating higher levels of spirituality. The mean score was 38 (*SD* = 9.2). The Cronbach's alpha for this study was .91. For the average person in this study, spirituality was moderate. Peterman et al. (2002) reported mean of 38.5 (*SD*= 8.1) and Cronbach's alpha of .87. Brady et al. (1999) also reported Cronbach's alpha of .87 and no mean scores.

Self-efficacy was measured with the SCSES. For this study, the mean was 30.3 (*SD*= 8.2) with Cronbach's alpha reliability of .87. The average self-efficacy for this group was moderate. The results of the SCSES for this study are similar to reports from Edwards (2001) and Jenerette (2004). Edwards (2001) reported mean of 32 (*SD*=7) and reliability of .89. Jenerette (2004) reported mean of 30.9 (*SD*=7.2) and Cronbach's alpha of .87.

Table 11 Descriptive statistics for Quality of life, spirituality and self-efficacy (N=90)

Test (Measurement)	Possible (Test) Range	Sample Range	Median	<i>M</i>	<i>SD</i>	Cronbach's alpha
Quality of life (FACT-G) total	0-108	19-107	75	72.3	20.1	.93
Physical well-being	0-28	0-28	16	16.2	7.0	.88
Social/family well-being	0-28	2-28	21	20.6	6.5	.84
Emotional well-being	0-24	4-24	19	17.8	5.0	.82
Functional well-being	0-28	2-28	18	17.7	7.1	.89
Spirituality (FACIT-Sp) Total	0-48	5-48	40	38	9.2	.91
Meaning/Peace	0-32	2-32	24	24.1	6.8	.88
Faith	0-16	3-16	16	13.8	3.3	.86
Sickle cell self-efficacy (SCSES)	9-45	10-45	31	30.3	8.2	.87

The hypothesized relationships among the primary outcome measures were assessed using Pearson correlation coefficients. The relationships among study variables in the regression model are linear and are represented in Figure 2. The scatterplot for the

three variables indicates that as spirituality and self-efficacy reports increase, QOL reports increase. There are direct, positive, linear relationships.

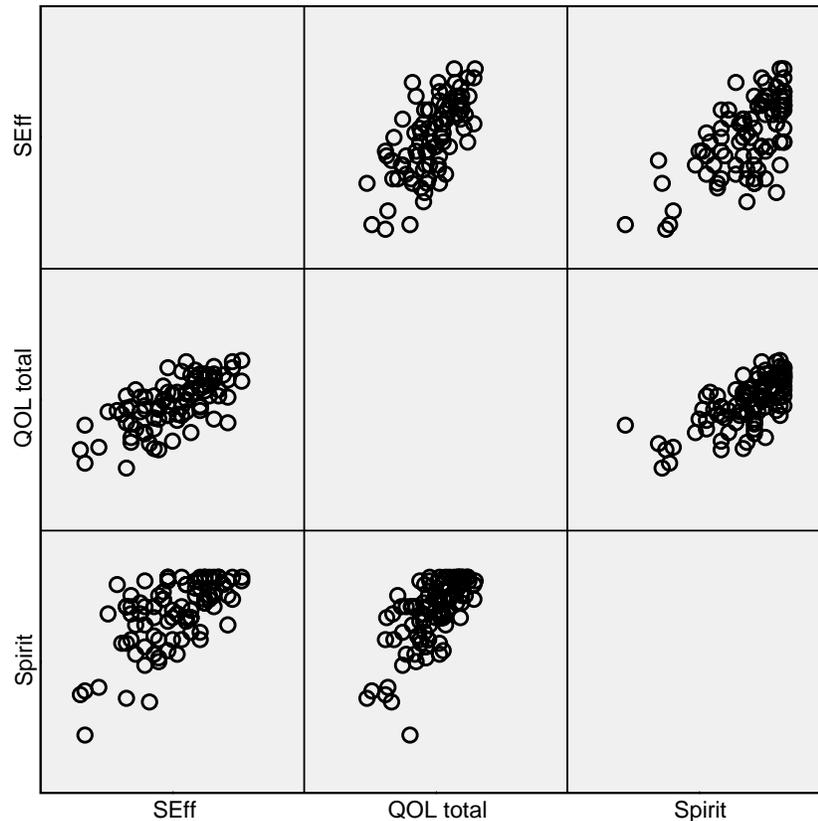


Figure 3. Scatterplot matrix of study variables

The results of the correlational analyses presented in Table 12, Table 13, and Table 14 show that all correlations were statistically significant ($p < .05$) and in all but two cases the correlations were moderate to large. The correlations between social/family well-being (S/FWB) and self-efficacy, and physical well-being (PWB) and spirituality were small. The S/FWB: PWB and S/FWB: functional well-being were significant at the

.05 level. In general, the results suggest that individuals who report high QOL in one area tend to report high QOL in all subset areas.

Correlational coefficients were also computed between the two spirituality subsets. The results of the correlational analyses presented in Table 14 show that all correlations were statistically significant and were greater than, or equal to .60. The results suggest that individuals who report high levels of spirituality in one area tend to report high levels of spirituality in both subset areas.

Table 15 shows the comparison of literature reported reliabilities and the reliabilities of this study. Brady et al. (1999) used the FACT-G and FACIT-Sp in their study that examined 161 patients with cancer and/or HIV infections/AIDS. Brady et al. reported Cronbach's alpha on the FACT-G was .72 to .85 and .87 for the FACIT-Sp. Cotton et al. (1999) examined 142 patients with breast cancer and did not report reliabilities for their study. Edwards (2001) in the one-year follow-up study reported the Cronbach's reliability for the original SCSES study as .89. Generally, the reliabilities of this study are similar to literature reports except for FACT-G. The reliabilities for FACT-G in this study are higher than those reported in the literature.

Cooper-Effa et al. (2001) investigated the role of spirituality among patients with SCD. The authors reported Cronbach's alpha as .88. The 72 patients who were assessed responded to the Spiritual Well-Being Scale designed by Ellison (1993).

Edwards et al. (2001), Jenerette (2004), and Lenoci et al. (2002) used the disease specific SCSES to measure self-efficacy among adults with SCD. Table 15 shows the literature reported reliabilities compared with the reliabilities for this study. Edwards et

al. (2001) did not report the reliability for the one-year follow-up study. The reported reliability for the instrument validation was .89 (Edwards et al., 2000). Lenoci et al. (2002) reported the reliability of the SCSES as .88. In Jenerette's 2004 study, a Cronbach's alpha of .87 was reported.

Hypothesis one.

Hypothesis one stated that there is a positive correlation between spirituality and QOL in adults with SCD. Pearson correlation coefficient was performed to test the relationship between spirituality and QOL. As shown in Table 15, the correlation between spirituality and QOL is positive and significant, $r(88) = .68, p < .05$. Hypothesis one was supported. As the level of spirituality increases, report of QOL increases.

Cotton et al. (1999) used the FACT-G and FACIT-Sp for their study and verified a positive correlation between spirituality and QOL. The authors concluded that more spiritually well individuals reported high QOL and psychological adjustment. Bartlett et al. (2003), who concluded that spiritual wellness enabled decreased reports of symptom load, later supported this. Spirituality can benefit health by providing purpose, meaning, and a positive mindset (Coyle, 2002; Frey et al., 2005) that ultimately contributes hope and optimism (Hill & Pargament, 2003; Matheis et al., 2006) to one's mindset and future life.

Bartlett et al. (2003) evaluated spirituality, well-being, and QOL among individuals with Rheumatoid Arthritis. The authors concluded, "spiritual individuals may be more resilient to the host of challenges imposed by a chronic illness" (p.782). The

authors were able to link spirituality with well-being and identified spirituality as one of “several known variables that influence the course of health over an individual’s lifetime” (p. 782). Spirituality can produce hardiness and influences the individual’s QOL. Spirituality was associated with happiness and positive perceptions (Bartlett, 2003). By experiencing positive feelings and attending to positive elements of life, individuals can improve their QOL.

Krupski, Kwan, Fink, Sonn, Maliski et al. (2006) examined the relationship among spirituality and QOL in individuals with prostate cancer. The authors used the FACIT-Sp to measure spirituality. The results of the study demonstrated that spirituality was significantly associated with and influenced QOL. “More spirituality is associated with better psychosocial and physical health related QOL” (Krupski et al., 2006, p. 129).

Brady et al. (1999) concluded that “Meaning/Peace on the spirituality measure was the best predictor of contentment with QOL” (p. 423). The authors used both the FACT-G and FACIT-Sp to investigate spirituality and QOL among individuals with cancer and HIV/AIDS. As noted in Table 15, Brady et al. reported reliabilities less than this current study. However, consistent with this study, Meaning/Peace is a strong factor of spirituality as it relates to QOL. Faith in both studies showed lower correlations with QOL. Brady et al. reported the correlation of faith with total QOL as .36. In this study, as noted in table 12, the correlation of faith with QOL is .48.

For this study, there is a positive and significant correlation between spirituality and QOL, $r(88) = .68, p < .05$. As the level of spirituality increased, reports of QOL increased.

Table 12 Pearson correlations among study variables (N = 90)

	Self-efficacy	Spirituality	QOL total
FACT-G (total)	.67**	.68**	-
Physical well-being	.49**	.37**	.77**
Social/Family well-being	.27*	.64**	.66**
Emotional well-being	.70**	.53**	.81**
Functional well-being	.66**	.66**	.86**
FACIT-Sp	.63**	-	.68**
Meaning/Peace	.64**	.96**	.68**
Faith	.42**	.80**	.48**
Sickle Cell Self-Efficacy Scale (SCSES)	-	.63**	.67**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table 13. Pearson correlations among QOL sub-scales (N = 90)

	PWB	SWB	EWB	FWB
Physical well-being (PWB)	-	.25*	.59**	.53**
Social/Family well-being (S/FWB)	.25*	-	.35**	.45**
Emotional well-being (EWB)	.59**	.35**	-	.66**
Functional well-being (FWB)	.53**	.45**	.66**	-
QOL total	.77**	.66**	.81**	.86**

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Table 14. Pearson correlations among Spirituality sub-scales (N = 90)

	Meaning/Peace	Faith
Meaning/Peace	-	.60**
Spirituality total	.96**	.80**

** Correlation is significant at the 0.01 level (2 tailed)

Table 15 Reliabilities of present study compared to literature reported studies

Scale (measurement)	Author- reported	Current study	Brady et al., (1999)	Cotton et al., (1999)	Jenerette (2004)	Lenoci et al., (2002)	Edwards et al. (2001)	Krupuski et al., (2006)
Quality of life (FACT-G) total	.89	.93	.72 to .85	-				
Physical well-being	.82	.88	-	-				
Social/family well-being	.69	.84	-	-				
Emotional well-being	.74	.82	-	-				
Functional well-being	.80	.89	-	-				
Spirituality (FACIT-Sp)	.87	.91	.87	-				-
Meaning/Peace	.81	.88	.81	-				-
Faith	.88	.86	.88	-				-
Sickle Cell Self-Efficacy (SCSES)	.89	.87			.87	.88	.89 (original study)	

Note. Blank areas represent items that are not applicable, and dashes indicate that data were not reported.

Hypothesis two.

Hypothesis two stated that there is a positive correlation between self-efficacy and QOL in adults with SCD. Table 15 indicates that the Pearson product moment correlation between self-efficacy and QOL is positive and significant, $r(88) = .67$, $p < .05$. Hypothesis two was supported.

Edwards et al. (2001) reported that self-efficacy scores were inversely related to changes in physical symptoms. The authors concluded that self-efficacy is an important factor in psychological and physical adjustment to chronic illness. In Edwards et al.'s (2001) study there was a positive correlation between self-efficacy and QOL.

Jenerette (2004) also reported on the negative impact of the number of complications and SCD crises/year on self-efficacy and QOL. The psychological impact of SCD undermines the physical aspects of the disease, depletes the individual's energy level, and prohibits successful completion of everyday tasks (Thomas & Taylor, 2002). These cyclical events of decreased QOL and decreased self-efficacy result in one's inability to perform daily activities, remain motivated, hopeful, and self-fulfilled. It then becomes difficult for the individual to cope with stress-producing situations. Bandura (1982) explained that self-efficacy helps to foster coping and response to stressors such as those produced by chronic illness.

Hypothesis three.

Hypothesis three stated that there is a positive correlation between self-efficacy and spirituality in adults with SCD. The Pearson product moment correlation coefficient

was positive and significant, $r(88) = .63, p < .05$. Hypothesis three was supported. As the level of spirituality increases, report of self-efficacy increases.

Cooper-Effa et al. (2001) concluded that spiritual well-being helped individuals with SCD cope more effectively with SCD associated pain. With increased hope, self-confidence, optimism and stability that result from spirituality (Coyle, 2002; Dyson et al., 1997; Frey et al., 2005; Hill & Pargament, 2003; Matheis et al., 2006), there is an overall sense of well being and self-efficacy. Individuals empowered with meaning, hope and purpose are more resilient and can overcome difficult circumstances (Narayanasamy, 2004) and travails associated with chronic illness such as SCD. Spirituality provides augmented hope and strength to face current and future challenges. Cotton et al. (1999) reported that individuals who were more self-efficacious demonstrated increased spirituality, a fighting spirit and psychological adjustment.

Nosek and Hughes (2001) in a literature review of qualitative studies examined the perceived sense of self in a psychospiritual context among women with disabilities. The authors found that spirituality is an important tool used by individuals with disabilities, and “spirituality can counteract negative odds” imposed by societal barriers and stereotypes (p. 24). Closely aligned with spirituality is self-efficacy. The authors explained that self-efficacy is “empowerment” and it fosters directional forces that enable latent spiritual resources to assist the individual to confidently rise to the challenges and burdens of chronic illness (Nosek & Hughes, 2001, p. 24).

Reicks, Mills, and Henry (2004) in their focus groups examined how cognitive variables such as self-efficacy and locus of control are influenced by participation in a

spiritually based weight loss program. The findings included reports that spiritual practices such as prayer and reading scripture improved and enhanced confidence to perform behaviors that enabled weight loss. The authors concluded that for some women, spirituality enhanced confidence and contributed to self-efficacy and attainment of goals.

Hypothesis four.

Hypothesis four stated that spirituality and self-efficacy predict QOL for adults with SCD. This hypothesis evaluated whether the independent variables (spirituality, self-efficacy) contribute to the dependent variable (QOL) in this population. A regression analysis was used to test this hypothesis. The Regression ANOVA tests “whether there really is a linear relationship between the variables by forming a F ratio of mean square region of regression to the residual, R^2 mean square” (Kinnear, 2000, p. 314). Significance appears in two places: the F tests reported as part of the ANOVA and the t test associated with independent variables in the coefficient table. In this analysis, F is significant (56%), $F(2, 87) = 56.1, p < .01$. The linear regression analysis revealed that spirituality and self-efficacy highly predict reports of QOL, with $R = .75$, $R^2 = .56$, and adjusted $R^2 = .55$. The R^2 of .56 describes the overall proportion of variance in the criterion variable QOL. Spirituality and self-efficacy account for more than half of the variance in QOL reports for this sample. Hypothesis four was supported.

These results suggest that adults with SCD who report high levels of spirituality and self-efficacy also report high levels of QOL. The results of this analysis indicated that spirituality and self-efficacy accounted for more than fifty percent, a significant

amount, of QOL variability, $R^2 = .56$, $F(2, 87) = 56.1$, $p < .01$, indicating that individuals' reports of spirituality and self-efficacy predict reports of QOL.

In summary, computed correlation coefficients among the three concepts were statistically significant at $p < .05$ level. Hypotheses one, two, and three were supported and demonstrated significant relationships among the variables. In general, the results suggest that adults with SCD report strong, positive (direct) relationships between spirituality and QOL, self-efficacy and QOL, and self-efficacy and spirituality. These correlation coefficients of .63 to .68 for the hypotheses reflect strong relationships (Salkind, 2006). Spirituality and self-efficacy highly predict reports of QOL.

Aim two. Explore relationships of socio-demographic variables and QOL.

Specific aim two was supported using a General Linear Model. The multifactorial analysis of variance (multifactorial ANOVA) is used for “analyzing the simultaneous effects of two or more independent variables (factors) on a dependent variable” (Corston & Colman, 2003, p. 84). The differentiation of the multifactorial ANOVA from one-way ANOVA is the inclusion of interaction terms in the statistical model (Corston & Colman, 2003). The interaction looks at differences among several group means by apportioning the total variance in the dependent variable into effects due to each of its factors (main effects), interaction between factors, and error variances (Corston & Colman, 2003).

The dependent variable is QOL. The factors are between subjects and are age, gender, household income, levels of education, frequency of hospitalization, and reported SCD genotype. Gender has two factors, male and female. Household income has six factors

(less than \$10,000, \$10,000 to \$19,999, \$20,000 to \$34,999, \$35,000 to \$49,000, \$50,000 to \$60,000, and more than \$60,000 per year). Level of education has five factors (less than high school, high school diploma, some college, Bachelor's degree, and graduate degree). Marital status has six factors (single, married, divorced, separated, widow, other). Genotype has three factors (HBSS, HbSC, Sickle Beta Thalassemia).

Table 16 shows the summary of the general linear model. The ANOVA indicated no significant interaction among demographic variables, spirituality, and self-efficacy, but significant main effects for spirituality and self-efficacy. The significant main effects are spirituality, $F(1, 56) = 17.35, p < .05, h^2 = .066$ and self-efficacy, $F(1, 56) = 8.03, p < .05, h^2 = .346$.

The partial eta squared (h^2) tells how well the independent variables describe the variation in the dependent variable. Partial eta squared for spirituality of .066 means that 6.6% of the dependent variable (QOL) is explained by spirituality (independent variable). That is, spirituality accounts for 6.6% of the total variance in QOL. Partial eta squared of .346 for self-efficacy means that 34.6% of variation in QOL is explained by self-efficacy. That is, self-efficacy accounts for 34.6% of the total variance in QOL. The relationships between QOL, spirituality, and self-efficacy are significant. There is no significant interaction between QOL, self-efficacy, spirituality and specified demographic variables (age, gender, household income, levels of education, frequency of hospitalization and reported SCD genotype), as assessed by the general linear model. However, as demonstrated by high partial eta squared (h^2), genotype, educational level, household income account for variation in reports of QOL. Educational level accounted for 26%,

household income accounted for 40%, and genotype accounted for 30% variation in QOL reports.

Table 16. General Linear Model

Source	<i>df</i>	Mean square	F	<i>sig</i>	Eta square (h^2)
D1-genotype	2	289.29	2.03	.14	.303
D4-age	1	43.61	.31	.58	.000
D5-gender	1	4.351	.03	.86	.001
D6-Educational level	4	159.67	1.12	.36	.257
D7- household income	5	141.27	.99	.43	.397
D8-marital status	5	126.49	.89	.50	.015
D9-hospitalization	1	142.12	1.0	.32	.033
Self-efficacy	1	1146.70	8.03	.01	.346
Spirituality	1	2475.88	17.35	.00	.066

D1: SCD genotype has three factors (HbSS, HbSC, Sickle Beta Thalassemia)

D4: age

D5: Gender has two factors, male and female.

D6: Level of education has five factors (less than high school, high school diploma, some college, Bachelor's degree, and graduate degree).

D7: Household income has six factors (less than \$10,000, \$10,000 to \$19,999, \$20,000 to \$34,999, \$35,000 to \$49,000, \$50,000 to \$60,000, and more than \$60,000 per year).

D8: Marital status has six factors (single, married, divorced, separated, widow, other).

D9: Frequency of hospitalization within last year

Discussion

The present study had two aims: 1) describe the relationships among spirituality, self-efficacy, and perceived QOL in adults with sickle cell disease; and 2) explore variation in these relationships based on selected demographic characteristics of age, gender, household income, levels of education, frequency of hospitalization, and reported SCD genotype.

Statistically significant relationships (correlations) were found between (a) spirituality and QOL, (b) self-efficacy and QOL, and (c) self-efficacy and spirituality in adults with SCD. The relationship of QOL, spirituality, and self-efficacy showed significant main effects but no significant interaction with demographic variables.

This study supports the findings of previous studies that spirituality is associated with outcome and QOL (Landis, 1966; Cooper-Effa, 2001). The person who is spiritually healthy has greater satisfaction with life, is able to cope with chronic illness, and able to manage day to day tasks of life. Reports of self-efficacy and spirituality predict QOL among adults with SCD.

Limitations

It is the researcher's hope that findings and results of this study will be useful to researchers and healthcare professionals who seek to improve QOL for individuals with SCD. There are several limitations to this research study that make it necessary to interpret study findings with caution. These limitations are shared with the hope of strengthening future research studies.

First, this study utilized a convenience sample of adults with SCD. By using a convenience sample, the investigator hindered the ability to generalize the results from this study to broader populations. The sample of this study looked similar to other national studies among individuals with SCD. Second, self report bias may have been introduced by participants responding to sensitive personal information such as household income and educational level. Third, this cross-sectional study did not allow for measurement of variables across time in the same subjects, limiting cause and effect conclusions. Fourth, the volunteer responders may be different from non-responders. Fifth, there may be the element of recall bias of events over the past seven days. The individual's reports may be different along the time course as the individual recalibrates feelings, perceptions, and responses over time.

Conclusions

Despite the limitations mentioned above, this study represents the only one to the author's knowledge that has looked at the relationship of combined variables of QOL, spirituality and self-efficacy in persons with SCD. The results of this study give support to the case for including spirituality in health assessments and intervention, incorporating a biopsychosociospiritual model in healthcare delivery and planning of culturally appropriate interventions.

Nurses and healthcare providers must incorporate an integrated, holistic framework that intentionally includes spirituality as a dimension of assessment and care. Care should be individualized and culturally appropriate for all individuals, especially those with chronic illness. Spirituality and self-efficacy are important factors contributing

to QOL in adults with SCD, and these factors should be incorporated into the nurse's assessment and planning. Further investigation of these relationships in individuals from other settings is needed. Including qualitative inquiry may also help to further clarify the relationship among these variables.

The experience of QOL for adults with SCD is complex and needs study that incorporates biopsychosociospiritual aspects that must be integrated for holistic care. This complex phenomenon requires in-depth investigation. This study has contributed additional knowledge regarding the relationship of spirituality, self-efficacy, and QOL in adults with SCD.

Implications for Nursing

Results of the current study provide further evidence that there is a strong relationship among QOL, spirituality, and self-efficacy in individuals with chronic illnesses and specifically adults with SCD. Nurses caring for individuals with SCD can better plan interventions by incorporating care that employs spirituality and self-efficacy into self-care models for QOL.

Nurses caring for individuals with SCD should be aware of the important role spirituality plays in reports of high QOL and self-efficacy in chronic illness self-care management. Nurses must incorporate spiritual assessment into nursing management and care planning. Healthcare consumers must be encouraged to use elements of their spirituality to maintain holistic self-management. Nurses and other healthcare providers should include a biopsychosociospiritual approach to care delivery. There should be intentional inclusion of spirituality in care delivery models and research pertaining to

QOL. The inclusion of spirituality should be void of religiosity and include individuals of varying faith.

Narayanasamy (2004) suggested nurses include and incorporate individualized, holistic elements of spiritual care into practice and care delivery. Some of the practices included active listening, showing genuine, unconditional acceptance of patients' idiosyncrasies, use humor, and show humility. In addition, a spiritual assessment should be done on all patients. In doing a spiritual assessment the nurse can ask the patient questions such as "*what gives you a sense meaning or purpose in your life, what do you think is going to happen to you?*" (Narayanasamy, 2004, p.1143), and *how do you cope with your illness and manage your day-to-day activities?*

The proposed theoretical model for this study provided an understanding of chronic illness and related factors that affect QOL. The theoretical framework of this study was supported and suggests spirituality is an integral part of QOL and self-efficacy. Further inquiry on the impact that spirituality and self-efficacy have on symptom load needs to be done. This elucidation will have clinical impact and help in initiation of culturally appropriate programs. Nurses should be aware of the impact of self-efficacy and spirituality on QOL and incorporate these elements into assessment and care planning. The framework provided direction for the program of research needed to understand QOL among individuals with SCD and the initiation of self-care interventions.

Research Recommendations

In summary, the goal of this study was to examine the relationships among QOL, spirituality, and self-efficacy in adults with SCD, and to identify variations associated with demographic variables. On the basis of the literature review, this is the first reported study describing combined variables of spirituality, self-efficacy, and QOL. Findings from this study provide important information on the relationship among the combined variables and suggest that this information must be included in care planning for adults with SCD.

Future studies should be done with the inclusion of qualitative inquiry. Including qualitative inquiry with the quantitative assessment of QOL, spirituality and self-efficacy, may help to identify unique themes germane to adults with SCD. In this study, there was the tendency for some of the participants in the mailed surveys to add their feelings in writing next to questions. Possibly the qualitative aspect of self-care in the presence of chronic illness predisposes individuals to the tendency of trying to articulate struggles; expose unique, intricate day-to-day patterns of self care, and report self-efficacious management.

Replication of relationships identified in this study is needed. In addition to inquiry among individuals with SCD, the replication studies should include individuals who have other chronic illnesses. A longitudinal study at several points in time would clarify if these relationships exist over time. A multi-center replication of the current study may enhance credibility and generalizability of these findings. A comparison of a group of individuals without SCD would help to identify the importance of inclusion of the

biopsychosociospiritual approach, especially with individuals with chronic illness. Other studies should look at symptom management with reports of spirituality. There may be differences in clinical presentations based on variation of spirituality reports.

It is known that spirituality increases resilience in the face of illness. The mechanism through which spirituality may influence coping, illness adjustment, and long-term outcomes needs to be investigated among adults with SCD. Management of chronic illness is continuous and long term, and individuals should be encouraged to institute self-care strategies and manage day-to-day activities (Thorne & Peterson, 2001).

Finally, further evaluation of Sickle Beta Thalassemia occurring only in females of this population needs to be explored in future studies. In this study, the distinction was not made among different types of Sickle Beta Thalassemia.

APPENDIX A

INVITATION LETTERS, STUDY GUIDELINES, MEASUREMENT TOOLS,
MAIL-OUT PACKET



Sickle Cell Disease Association of Dallas
320 S. R L Thornton Freeway, Suite 110
Dallas, TX 75203
214-942-1262 (o), 214-948-9517 (f)
www.sicklecelldallas.org

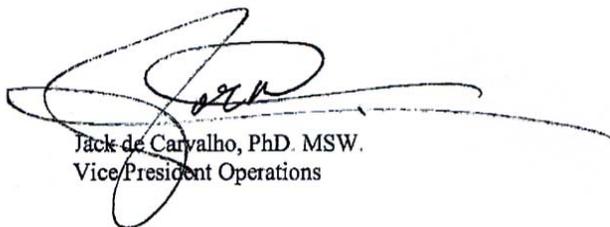
Dear Survey Participant:

As Vice-President of the Sickle Cell Disease Association, Dallas, I would like to introduce Maxine Adegbola, a Nursing doctoral student at the University of Texas, who is requesting your voluntary participation in completing the attached survey pertaining to your quality of life from having sickle cell disease.

This survey is being conducted through the University of Texas at Arlington. The Sickle Cell Disease Association, Dallas has given Ms. Adegbola permission to conduct the study. I encourage your participation in this anonymous survey. Please return your survey using the enclosed self addressed stamped envelope.

Your anonymous responses will help in planning services for adults with sickle cell disease, and may ultimately improve healthcare delivery for others. The summary results from the survey will be available from me after about six months.

Thank you for your assistance and support. If you have any questions, you can contact me at 214-942-1262.



Jack de Carvalho, PhD. MSW.
Vice President Operations

Dear Survey Participant:

Hello, my name is Maxine Adegbola, and I am a student in the Nursing PhD program at the University of Texas at Arlington (UTA). I am interested in quality of life issues among individuals like you, with sickle cell disease (SCD). I invite you to participate in a survey research study that I am conducting as part of my program completion requirements. It will not take more than 20 minutes

The reason for the study is to learn more about quality of life for adults with SCD. Little is known about the relationship of factors that may affect quality of life for adults with sickle cell disease. Your participation is important, as your experiences will help in planning healthcare interventions that are targeted to the specific needs of persons with SCD.

You are receiving this request because you are 18 years of age or older, and have sickle cell disease. After you have read the rest of this letter, please complete the survey that is in this packet. When you have answered all of the questions, put the completed survey in the enclosed stamped, addressed envelope, and mail the envelope.

1. Your participation is completely voluntary.
2. You are free to withdraw/stop participating at any time.
3. If you choose not to participate, your services will not be affected.
4. Do not put your name or any identifying marks on your survey.
5. I will be the only one who will see your responses, and I will have no way of identifying your physical addresses or any other personal information about you.
6. All individual responses will be kept confidential.
7. Although your responses will remain anonymous, your data/answers may be combined with data /answers of others and submitted for presentation at conferences or in publications in professional magazines, as group data.
8. You are encouraged to answer all questions, but you may choose not to answer any questions that make you uncomfortable. There are no expected risks identified with this study. Future individuals will benefit from study results, which may help in planning health programs.
9. Your completion and return of this questionnaire indicates that you voluntarily consent to participate in this study.
10. For your time and effort in completing the survey, compensation of \$10.00 (ten dollars) is being offered to you if you fully complete the survey, and voluntarily disclose your name and mailing address on the enclosed white envelope. You must return the survey packet and white envelope in the brown stamped return envelope. Returning your packet within a week of receipt is appreciated. The

compensation will be mailed to you. In addition, the summary report, when results are available, will be mailed to you if you request it.

This project has been reviewed by the University of Texas at Arlington Institutional Review Board (IRB) for the protection of human subjects, and I have permission from the Sickle Cell Disease Association of Dallas. Any questions about the conduct of this project should be brought to the attention of Maxine Adegbola (principal investigator) at (214) 876-9767, or Dr. Carolyn Cason (sponsor), at the University of Texas at Arlington (817) 272-5781. Any questions about your rights as a research participant or an activity-related injury should be brought to the attention of the IRB Coordinator at (817) 272-3723, Arlington, Texas.

The survey starts on the following page. Please answer questions honestly, and in sequence.

Thank you for participating.

Maxine Adegbola

Maxine Adegbola, RN, MSN, PhD student



Quality of life in adults with Sickle Cell Disease

Thank you for participating in this study. Many of the questions may appear to be the same to you, but please answer each one of them as honestly as you can.

Answer the items in sequence without skipping questions.

There are no right or wrong answers – just give your first impression.

FACIT

ID

Instructions: Below is a list of statements that other people with your illness have said are important.

Please completely darken the circle that best indicates how true each statement has been for you during the past 7 days.

Shade Circles Like This--> ●
 Not Like This--> ⊗ ⊙

	Not at All	A little Bit	Somewhat	Quite a bit	Very much
1. I have a lack of energy.	<input type="radio"/>				
2. I have nausea.	<input type="radio"/>				
3. Because of my physical condition, I have trouble meeting the needs of my family.	<input type="radio"/>				
4. I have pain.	<input type="radio"/>				
5. I am bothered by side effects of treatment.	<input type="radio"/>				
6. I feel ill.	<input type="radio"/>				
7. I am forced to spend time in bed.	<input type="radio"/>				
8. I feel close to my friends.	<input type="radio"/>				
9. I get emotional support from my family.	<input type="radio"/>				
10. I get support from my friends.	<input type="radio"/>				
11. My family has accepted my illness.	<input type="radio"/>				
12. I am satisfied with family communication about my illness.	<input type="radio"/>				
13. I feel close to my partner (or the person who is my main support).	<input type="radio"/>				

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 Not Like This--> ⊗ ⊙

ID

Not at All A little Bit Somewhat Quite a bit Very much

14. Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box: Prefer not to answer.
- I am satisfied with my sex life.
15. I feel sad.
16. I am satisfied with how I am coping with my illness.
17. I am losing hope in the fight against my illness.
18. I feel nervous.
19. I worry about dying.
20. I worry that my condition will get worse.
21. I am able to work (include work at home).
22. My work (include work at home) is fulfilling.
23. I am able to enjoy life.
24. I have accepted my illness.
25. I am sleeping well.
26. I am enjoying the things I usually do for fun.
27. I am content with the quality of my life right now.
28. I feel peaceful.
29. I have a reason for living.
30. My life has been productive.
31. I have trouble feeling peace of mind.
32. I feel a sense of purpose in my life.

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 12/05/2006 33001
 Telephone created 10/26/06 aab

3071330018

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 Not Like This--> ⊗ ⊙

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	Not at All	A little Bit	Somewhat	Quite a bit	Very much
33. I am able to reach down deep into myself for comfort.	⊙	⊙	⊙	⊙	⊙
34. I feel a sense of harmony within myself.	⊙	⊙	⊙	⊙	⊙
35. My life lacks meaning and purpose.	⊙	⊙	⊙	⊙	⊙
36. I find comfort in my faith or spiritual beliefs.	⊙	⊙	⊙	⊙	⊙
37. I find strength in my faith or spiritual beliefs.	⊙	⊙	⊙	⊙	⊙
38. My illness has strengthened my faith or spiritual beliefs.	⊙	⊙	⊙	⊙	⊙
39. I know that whatever happens with my illness, things will be ok.	⊙	⊙	⊙	⊙	⊙

Adegbola Study
 12/05/2006 33001
Teleform created 10/26/06 ewb

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ID

The following questions ask about how sure you are in dealing day-to-day with sickle cell disease. There are no right or wrong answers, we just want to know what you think. So for each question tell us how sure you are by shading the circle that best tells us how you feel. Please answer every

Instructions: Please use a BLACK PEN for completing the survey. Do not use pencil.

Shade Circles Like This--> ●
Not Like This--> ⊗ ⊙

	Not at all sure	Not Sure	Neither	Sure	Very Sure
40. How sure are you that you can do something to cut down on most of the pain you have when having a pain episode?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
41. How sure are you that you can keep doing most of the things you do day-to-day?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
42. How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
43. How sure are you that you can reduce your sickle cell disease pain by using methods other than taking extra medication?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
44. How sure are you that you can control how often or when you get tired?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
45. How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
46. As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
47. How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
48. How sure are you that you can deal with the frustration of having sickle cell disease?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

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Not Like This--> ⊗ ⊙

ID

1. Type of sickle cell disease you have:

- SS SC Sickle Beta Thalessemia Other: _____
PLEASE PRINT CLEARLY
- Or Sickle Cell Trait

2. At what age did you know that you had sickle disease?

3. Country of birth: _____
PLEASE PRINT CLEARLY

4. Age:

5. Gender: Male Female

6. Education (please mark highest educational level):

- Less than high school graduate Bachelor's degree
 High school diploma Graduate degree
 Some college

7. Household Income:

- Less than \$10,000 per year \$35,000 - \$49,999 per year
 \$10,000 - \$19,999 per year \$50,000 - \$60,000 per year
 \$20,000 - \$34,999 per year More than \$60,000

8. Marital Status:

- Single Married Divorced Separated Widow Other

9. Within the last year, how many times have you been hospitalized?

- 0 4 8
 1 5 9
 2 6 10
 3 7

Thank you for participating.
Please return this completed survey by mail in the self-addressed envelope to:

Maxine Adegbola
13738 Peyton Drive
Dallas, Texas 75240

Page 5 of 5

DEC 20 2006

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APPENDIX B

INSTITUTION REVIEW BOARD APPROVAL



THE UNIVERSITY
OF TEXAS
AT ARLINGTON

Office of Research
Integrity and Compliance

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January 16, 2007

Maxine Adegbola
Carolyn Cason, PhD
Nursing
19407

RE: Expedited Approval of Protocol

Title: *The Relationship among Spirituality, Self-Efficacy and Quality of Life in Adults with Sickle Cell Disease*

IRB No.: 07.082s

The University of Texas at Arlington Institutional Review Board (UTA IRB) Chair (or designee) has determined that this research is eligible for expedited review in accordance with Title 45 CFR 46.110(a)-(b)(1), 63 FR 60364 and 63 FR 60353. The IRB Chairman (or designee) approved the protocol effective December 20, 2006. It is further found that the above referenced study also qualifies for a waiver of the requirement to obtain Informed Consent under the federal guidelines for the protection of human subjects as referenced at Title 45 CFR 46.116(d)(1)-(4). The procedures indicated in the study provide that:

- (1) the research involves no more than minimal risk to the subjects;
- (2) the waiver will not adversely affect the rights and welfare of the subjects;
- (3) the research could not practicably be carried out without the waiver, and
- (4) whenever appropriate, the subject will be provided with additional pertinent information after participation.

Pursuant to §46.117(c)(2), the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

Your study is approved for a period not to exceed one year. Please note that your study will be scheduled for continuing review before December 19, 2007. Please be advised that as the principal investigator, you are required to report local adverse (unanticipated) events to this office within 24 hours. In addition, pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, “ promptly report to the IRB **any** proposed changes in the research activity, and to ensure that such changes in approved research, during the period for which IRB approval has already been given, are **not initiated without prior IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject.”



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March 21, 2007

Maxine Adegbotu
Carolyn Cason, PhD
Nursing
Box 19407

RE: Minor Modification Approval Letter

Title: *The relationship among spirituality, self-efficacy and quality of life in adults with sickle cell disease*

IRB No.: 07.082s

The UTA Institutional Review Board (UTA IRB) Chair (or designee) reviewed and approved the modification(s) to this protocol on **March 21, 2007** in accordance with Title 45 CFR 46.110(b)(2). Therefore, you are authorized to conduct your research. The modification(s), indicated below, was deemed minor and appropriate for expedited review.

- Protocol modified to delete collaborator Dr Bronte, Memorial Regional Hospital.
- Protocol modified to add the Sickle Cell Disease Association, Dallas.
- Survey changed to a mail survey with a \$10 incentive for completed and returned questionnaires.

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB any proposed changes in the research activity, and ensure that such changes in approved research, during the period for which IRB approval has already been given, **are not initiated without IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject."

The modification approval will additionally be presented to the convened board on April 10, 2007 for full IRB acknowledgment [45 CFR 46.110(c)]. All investigators and key personnel identified in the protocol must have documented *Human Subjects Involved in Research (Tier II) Training* or other UTA approved compliance education in the responsible conduct of human subject research on file with the UTA Office of Research Integrity and Compliance (ORIC).

The UTA Office of Research Integrity and Compliance appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact this office by calling (817) 272-2775 or (817) 272-3723.

Sincerely,

Judy Wilson, PhD
Associate Professor
UTA IRB Clinical Vice-Chair

April 19, 2007

Maxine Adegbola
Carolyn Cason, PhD
Nursing
Box 19407

RE: Minor Modification Approval Letter

Title: *The Relationship among Spirituality, Self-Efficacy and Quality of Life in Adults with Sickle Cell Disease*

IRB No.: 07.082s

The UTA Institutional Review Board (UTA IRB) Chair (or designee) reviewed and approved the modification(s) to this protocol on **April 19, 2007** in accordance with Title 45 CFR 46.110(b)(2). Therefore, you are authorized to conduct your research. The modification(s), indicated below, was deemed minor and appropriate for expedited review.

- Protocol modified to include an electronic version of the survey
- Protocol modified to include an additional distribution list from Children's Medical Center of Dallas

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, "promptly report to the IRB any proposed changes in the research activity, and ensure that such changes in approved research, during the period for which IRB approval has already been given, **are not initiated without IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject."

The modification approval will additionally be presented to the convened board on May 8, 2007 for full IRB acknowledgment [45 CFR 46.110(c)]. All investigators and key personnel identified in the protocol must have documented *Human Subjects Involved in Research (Tier II) Training* or other UTA approved compliance education in the responsible conduct of human subject research on file with the UTA Office of Research Integrity and Compliance (ORIC).

The UTA Office of Research Integrity and Compliance appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact this office by calling (817) 272-0867.

Sincerely,

Judy Wilson, PhD
Associate Professor
IRB Clinical Vice-Chair



THE UNIVERSITY
OF TEXAS
AT ARLINGTON

Office of Research
Integrity and Compliance

Box 19188
202 E. Border
Arlington, Texas
76019-0188

T 817.272.3723
F 817.272.1111
www.uta.research

May 8, 2007

Maxine Adegbola
Carolyn Cason, PhD
Nursing
The University of Texas at Arlington
Box 19407
Arlington, TX 76019

RE: Minor Modification Approval Letter

TITLE: *The Relationship among Spirituality, Self-Efficacy and Quality of Life in Adults with Sickle Cell Disease*

IRB No.: 07.082s

The UTA Institutional Review Board (UTA IRB) Chair (or designee) reviewed and approved the modification(s) to this protocol on **May 8, 2007** in accordance with Title 45 CFR 46.110(b)(2). Therefore, you are authorized to conduct your research. The modification(s), indicated below, was deemed minor and appropriate for expedited review.

- Protocol modified to include a recruitment poster

Pursuant to Title 45 CFR 46.103(b)(4)(iii), investigators are required to, “promptly report to the IRB any proposed changes in the research activity, and ensure that such changes in approved research, during the period for which IRB approval has already been given, **are not initiated without IRB review and approval** except when necessary to eliminate apparent immediate hazards to the subject.”

The modification approval will additionally be presented to the convened board on June 12, 2007 for full IRB acknowledgment [45 CFR 46.110(c)]. All investigators and key personnel identified in the protocol must have documented *Human Subjects Involved in Research (Tier II) Training* or other UTA approved compliance education in the responsible conduct of human subject research on file with the UTA Office of Research Integrity and Compliance (ORIC).

The UTA Office of Research Integrity and Compliance appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact this office by calling (817) 272-0867.

Sincerely,

Patricia Turpin, PhD, RN, CNA, BC
Associate Clinical Professor
IRB Clinical Chair

APPENDIX C

COLLABORATORS' SUPPORT LETTERS



Sickle Cell Disease Association of Dallas
320 S. R L Thornton Freeway, Suite 110
Dallas, TX 75203
214-942-1262 (o), 214-948-9517 (f)
www.sicklecelldallas.org

3/15/2007

Maxine Adegbola
13738 Peyton Drive
Dallas, Texas 75240

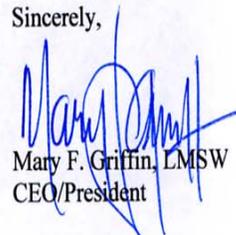
Re: Institutional permission letter to conduct study

Dear Ms. Adegbola,

This letter is to confirm our willingness to assist you in your research survey to examine the relationship among spirituality, self-efficacy, and quality of life among adults with sickle cell disease who use the services of the Sickle Cell Disease Association of Dallas. You have our permission to use the mailing list of adult clients who use our services for your survey.

We would appreciate a summary of your findings, and acknowledgement of our participation in any publication or presentation related to this research study.

Sincerely,



Mary F. Griffin, LMSW
CEO/President

Southwestern Comprehensive
Sickle Cell Center

George R. Buchanan, M.D.
Center Director

Shirley Miller
Manager
Advocacy/Community Relations

Sandra Richardson
Administrative Coordinator

4/11/07

Maxine Adegbola
13738 Peyton Drive
Dallas, Texas 75240

Re: Permission letter to use mail distribution list

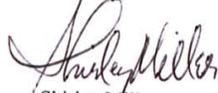
Dear Ms. Adegbola,

This letter confirms my willingness to assist you in your research survey to examine the relationship among spirituality, self-efficacy, and quality of life among adults with sickle cell disease who are on my distribution list. You have my permission to use my distribution mailing list of adults with sickle cell disease, and address your questionnaire to 'Survey Participant-SCD'.

I will send an e-mail to the individuals on the distribution list to inform them of the planned survey, mail procedures, and invite them to participate in the survey. I will inform the participants that their names will not be released, only their electronic or regular addresses and the survey will be addressed to Survey Participant-SCD.

I wish you all the best in your research career.

Sincerely,



Shirley Miller
Community Relations Manager

Other Participants: The University of Oklahoma Health Science Center, Scott & White Clinic - Texas A & M Health Science Center,
The University of Texas Medical Branch at Galveston and the Sickle Cell Disease Association of America - Dallas Chapter

1935 Motor Street / Dallas, Texas 75235 / 214-456-8716 Telefax 214-456-5097 sicklecell@utsouthwestern.edu

APPENDIX D
FOLLOW-UP MAIL OUT POSTCARDS

Follow-up mail out postcards

The mail out of the survey packet took place on day one. Follow up postcards were mailed out on day seven and day 14.

Sample mail out postcard day seven

Recently you were invited to participate in an anonymous survey regarding quality of life with sickle cell disease. This postcard serves as a reminder for you to complete the study, and return in the stamped addressed envelope. If you have already responded, thank you for participating. If you not yet responded, please do so. Remember the results from this study will be available from the Director in about six months.

Thank you,

Maxine Adegbola

Sample mail out postcard day 14

We are in the process of completing the data collection period for the Quality of Life with Sickle cell Disease survey. Again, thanks to those who mailed in their responses. This is the last reminder for those who have not yet responded, to do so. The survey takes less than 20 minutes to complete, and you have a stamped return envelope to use for mailing your responses.

Thank you very much for participating.

Maxine Adegbola

APPENDIX E

INSTRUMENT USE PERMISSION LETTERS

Reminder: AOL will never ask you to send us your password or credit card number in an email.

From: Peterman, Amy

To: Gabrielmaxine1@aol.com

Cc: k-webster@northwestern.edu

Subject: RE: FACIT-sp use for dissertation (Functional assessment of chronic illness)

Date: Thu, 29 Jun 2006 12:14:47 -0400

Dear Maxine,

Thank you very much for your interest in the FACIT-Sp. I'm not aware of any use of the instrument with people with sickle cell disease, so yours would be a novel project. The scale is available for use without permission. For an "official" copy of the scale, as well as scoring and psychometric information, you can go to the website www.facit.org. Some people have reported difficulty accessing what they need from this site, so I'm also copying Ms. Kimberly Webster. Ms. Webster fields most of the requests for information about the FACIT measurement system, so you may contact her if you do not find what you need on the website.

You probably already have this reference, but psychometric information can also be found in the following publication:

Peterman, A.H., Fitchett, G., Brady, M.J., Hernandez, L., & Cella, D. (2002). Measuring spirituality in people with cancer: the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being Scale (FACIT-SP). *Annals of Behavioral Medicine*, 49, 49-58.

Best of luck with your dissertation research!

Amy Peterman

Amy H. Peterman, Ph.D.
Associate Professor
Department of Psychology
University of North Carolina at Charlotte
9201 University City Blvd.
Charlotte, NC 28223
phone: 704-687-4764
fax: 704-687-3096
e-mail: ahpeterm@uncc.edu

yes you have permission and encouragement.

see www.facit.org for information.

dave

=====Original message text=====

On Wed, 28 Jun 2006 5:23:32 pm CDT gabrielmaxine1@aol.com wrote:

-----Original Message-----

From: Gabrielmaxine1@aol.com

To: d-cella@nwu.edu

Cc: maa5541@dcccd.edu

Sent: Wed, 28 Jun 2006 6:10:31 AM Eastern Daylight Time

Subject: Permission to use FACT-G for dissertation

=====End of original message text=====

David Cella, Ph.D.

Professor and Director, CORE

847.570.7370 - phone

847.570.8033 – fax

Thank you for your note. The instrument is mine so I can give you permission to use. My only request is a copy of the tool or protocol you used it with and a letter indicating why you want to use the instrument and how you expect it to help your agency.

Thank you for your interest.

Joseph Telfair, DrPH, MSW/MPH
Associate Professor
Maternal and Child Health
School of Public Health
University of Alabama at Birmingham
1665 University Blvd, Room 320
Birmingham, Alabama 35294-0022
205-934-7161 (Office)
205-934-1371 (Direct)
205-276-4222 (Mobile)
jtelfair@uab.edu

From: Gabrielmaxine1@aol.com [mailto:Gabrielmaxine1@aol.com]
Sent: Friday, October 01, 2004 6:50 AM
To: jtelfair@uab.edu
Subject: Permission to use instrument, Sickle Cell Self-efficacy scale

Dr. Telfair,
I write again to get permission to use the Sickle Cell Self-efficacy scale. I was unable to contact the primary author. My research area is caring for SCD population.
Thank you very much.

Maxine Adegbola
(PhD Nursing student at University of Texas at Arlington)
Research focus: Caring management of vulnerable populations, specific interest sickle cell disease
Home: 972 490 1233
Cell: 214 876 9767
"Nobody can make you feel inferior without your consent"..Eleanor Roosevelt

Good morning. Thank you for your email. You may delete the title. I ask two things. First, please be sure to reference us in any write-up. Second, could you please send me a copy of the final survey for our records?

Thank you and best wishes on your work.

Peace, Blessings and TTFN

Joseph Telfair, DrPH, MSW, MPH
Professor, Public Health Research and Practice
Department of Public Health Education
School of Health and Human Performance
University of North Carolina at Greensboro
437 HHP Building
1408 Walker Avenue
P.O. Box 26170
Greensboro, NC 27402-6170
Administrative Office Phone: (336) 334 - 3240
Direct Line: (336) 334 - 4777
Fax Number: (336) 334 - 3238
Mobile Phone: (205) 276 - 4222
email: j_telfai@uncg.edu
Website: <http://www.uncg.edu/phe/>

"Great Spirits have always found violent opposition from mediocrities. The latter cannot understand it when a man does not thoughtlessly submit to hereditary prejudices but honestly and courageously uses his intelligence."

----- Albert Einstein

"The blessing of success is its own revenge"

- Telfair, 1995

Dr. Telfair,

We have communicated in the past, and you gave permission for me to use the SCSES measurement. For my dissertation, I am looking at Self-efficacy, Spirituality and Quality of Life among adults with Sickle Cell Disease. I seek your permission to delete the title of the tool from the mail out survey. There will be no changes made to the items of the measurement. The reason for seeking your permission is for the numbering of the items to be sequential among all instruments being used, and flow would not be disrupted. The handling and analysis of items under the SCSES would not be changed.

Thank you

Maxine Adegbola

APPENDIX F

ELECTRONIC INTRODUCTORY EXPLANATION OF STUDY

Dear Survey Participant:

Hello, my name is Maxine Adegbola, and I am a student in the Nursing PhD program at the University of Texas at Arlington (UTA). I am interested in quality of life issues among individuals like you, with sickle cell disease (SCD). I invite you to participate in a survey research study that I am conducting as part of my program completion requirements. It will not take more than 20 minutes

The reason for the study is to learn more about quality of life for adults with SCD. Little is known about the relationship of factors that may affect quality of life for adults with sickle cell disease. Your participation is important, as your experiences will help in planning healthcare interventions that are targeted to the specific needs of persons with SCD.

You are receiving this request because you are 18 years of age or older, and have sickle cell disease. After you have read the rest of this letter, please complete the survey. When you have answered all of the questions, submit your responses.

1. Your participation is completely voluntary.
2. You are free to withdraw/stop participating at any time.
3. If you choose not to participate, your services will not be affected.
4. Do not put your name or any identifying marks on your survey.
5. I will be the only one who will see your responses, and I will have no way of identifying your physical addresses or any other personal information about you.
6. All individual responses will be kept confidential.
7. Although your responses will remain anonymous, your data/answers may be combined with data /answers of others and submitted for presentation at conferences or in publications in professional magazines, as group data.
8. You are encouraged to answer all questions, but you may choose not to answer any questions that make you uncomfortable. There are no expected risks identified with this study. Future individuals will benefit from study results, which may help in planning health programs.
9. Your completion and return of this questionnaire indicates that you voluntarily consent to participate in this study.
10. For your time and effort in completing the survey, compensation of \$10.00 (ten dollars) is being offered to you if you fully complete the survey within a week of receipt, and voluntarily disclose your name and mailing address electronically. The compensation will be mailed to you. In addition, the summary report, when

results are available, will be sent by Ms. Shirley Miller to all individuals on her distribution list.

The University of Texas at Arlington Institutional Review Board (IRB) for the protection of human subjects has reviewed this project, and has given permission to conduct this survey. Any questions about the conduct of this project should be brought to the attention of Maxine Adegbola (principal investigator) at (214) 876-9767, or Dr. Carolyn Cason (sponsor), at the University of Texas at Arlington (817) 272-5781. Any questions about your rights as a research participant or an activity-related injury should be brought to the attention of the IRB Coordinator at (817) 272-3723, Arlington, Texas.

The survey starts on the following page. Please answer questions honestly, and in sequence.

Thank you for participating.

Maxine Adegbola

Maxine Adegbola, RN, MSN, PhD student

.

Thank you for participating in this study. Many of the questions may appear to be the same to you, but please answer each one of them as honestly as you can.

Answer the items in sequence without skipping questions.

There are no right or wrong answers – just give your first impression.

APPENDIX G

INVITATION POSTER FLYER FOR STUDY

Sickle Cell Disease Quality of Life Survey

Are you?

- ✓ 18 years or older &
- ✓ have Sickle Cell Disease

Earn \$10...

- ✓ by completing the online survey
(if all requirements are met)

Go to...

<http://www.surveymonkey.com/s.asp?u=459283717365>

Help make a difference!

The information gained from this survey will help to provide better healthcare services for persons living with Sickle Cell Disease.



Contact Information:
M. Adegbola, R.N., MSN
maxscd@aol.com
214.876.9767

<http://www.surveymonkey.com/s.asp?u=459283717365>

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BIOGRAPHICAL INFORMATION

Maxine Adegbola

Maxine Adegbola is a NIH/NINR Summer Genetics Institute fellow and Nursing Instructor at El Centro College, Dallas, Texas. She received her Diploma in Nursing from the University Hospital of the West Indies, Jamaica; BSN and MSN from Hunter College, City University of New York, and is currently a PhD Nursing student at the University of Texas at Arlington. She has taught in the Associate Degree Nursing program at El Centro College, Dallas, Texas for 17 years. She was level coordinator at El Centro College for seven years, and Divisional and Assistant Director Nursing at Long Island College Hospital, Brooklyn , New York for three years.

In September, 2007 Maxine was recognized as a Fern Kyba fellow for her dissertation study “The Relationship among Spirituality, Self-Efficacy, and Quality of Life in adults with Sickle Cell Disease”.

In 2006, Maxine was awarded University Scholar for Academic Excellence at the University of Texas at Arlington, and received a mentee award from the National Coalition of Ethnic Minority Nurse Associations (NCEMNA). The same year she was awarded a Minority Recruitment and Retention Opportunity for Research (MIRROR) fellowship at University Texas Dallas Sickle Cell Disease Research Center.

She has made numerous presentations to healthcare professional groups. In May, 2006 she presented *La Participación Afroamericana en la investigación : Investigadores edificando confianza con Afroamericanos* at the 5th congress of *Internacional de Linguística: “Palabra, Silencio e Inexistencia, Cuernavaca, Mexico*. In October 2006, she presented to Nursing PhD students at the University of Texas at Arlington, *The Genomic Era: Where do we go from here?* This presentation focused on integrating genomics into Nursing practice and education. At the National Coalition of Ethnic Minority Nurse Associations (NCEMNA) March, 2007 annual conference, Maxine presented on *Relationship of Spirituality, Self-efficacy, and Quality of Life among Adults with Sickle Cell Disease*. Highlights of this presentation included lessons that were learned about the research process pertaining to individuals with sickle cell disease.

Her research interests include care of individuals with chronic illnesses, with emphasis on those with sickle cell disease. Her professional goals are to 1) construct a bio-psychosocialspiritual, culturally specific research and theory development program related to the health maintenance and prevention of illness exacerbation among global, vulnerable populations, with special focus on those with sickle cell disease, 2) develop and implement a module of study pertaining to genomic and genetic healthcare as it impacts the role of the nurse in health promotion, and 3) utilize her extensive experience in education, leadership, and clinical practice to effectively prepare students for careers in Nursing Science

She is actively involved in the Dallas Metroplex Black Nurses Association and volunteers with the Sickle Cell Disease Association, Dallas.

In addition to her professional interests, Maxine Adegbola enjoys reading and spending time with her family. She is an active member of Dallas Overcomers Church. She is married to her friend, Gabriel, and they have a gorgeous daughter, Joy. Maxine makes her home in Dallas, Texas.