Marquette University

e-Publications@Marquette

Dissertations (2009 -)   Dissertations, Theses, and Professional Projects

Spirituality And Religiosity In Adolescents With Sickle Cell Disease: A Descriptive Qualitative Study

Dora L. Clayton-Jones
Marquette University

SPIRITUALITY AND RELIGIOSITY IN ADOLESCENTS WITH SICKLE CELL DISEASE:
A QUALITATIVE STUDY

by

Dora L. Clayton-Jones, PhD(c), MSN, RN, CPNP

A Dissertation submitted to the Faculty of the Graduate School,
Marquette University,
in Partial Fulfillment of the Requirements for
the Degree of Doctor of Philosophy

Milwaukee, Wisconsin

May 2014

ABSTRACT
SPIRITUALITY AND RELIGIOSITY IN ADOLESCENTS WITH SICKLE CELL
DISEASE: A DESCRIPTIVE QUALITATIVE STUDY

Dora Clayton-Jones, PhD (c), MSN, RN, CPNP

Marquette University, 2014

Sickle cell disease (SCD) is a serious debilitating chronic illness and global health problem. Spirituality and religiosity have been shown to have positive correlations with their health outcomes. Research addressing the spiritual and religious needs of adolescents living with SCD is limited.

The aim of this descriptive qualitative study was to examine how adolescents (Mage = 16.2 years) with SCD describe and experience spirituality and religiosity. Nine adolescents completed two semi-structured interviews. Sickle Cell Disease Interview Guides were developed using the Spiritual Development Framework developed by Benson & Roehlkepartain (2008) as a guide. The framework provided a foundation for conceptualizing the spiritual element of human development. Sickle Cell Disease Interview Guides were used to elicit information on adolescents' beliefs, spirituality, and religiosity. Participant Demographic Forms were completed by each adolescent and used to collect information regarding their demographics, SCD histories, and religiosities. Parent Demographic Forms were completed by each parent and used to collect information regarding parents' demographics and religiosities.

Data were analyzed using a template analysis style and a concurrent analysis process of data reduction, data display, and conclusion drawing/verification. The Spiritual Development Framework was used as a guide in constructing components of the analysis template. Adolescents verbalized their thoughts regarding their spirituality and religiosity. The adolescents believed that religiosity is personal, meaningful, and should be respected. Four main themes emerged to include: spirituality and religiosity as coping mechanisms, shaping of identity, the influence of beliefs on health and illness, and the expectations for health care providers. The theme spirituality and religiosity as coping mechanisms included six threads to include: interconnecting with God, interconnecting with others, interconnecting with creative arts, scriptural metanarratives, transcendent experiences, and acceptance and finding meaning. The theme expectations for health providers included two threads to include: religiosity is private/personal and sharing spiritual and religious beliefs is risky.

The current study examined spirituality and religiosity as described and experienced by adolescents with SCD. The current study highlights the role of spirituality

and religiosity in an age-specific population living with sickle cell disease. Exploring spirituality and religiosity may lead to innovative interventions improving quality of life.

ACKNOWLEDGEMENTS

Dora Clayton-Jones, PhD (c), MSN, RN, CPNP

I dedicate the accomplishment of this project to GOD. Through You I live, I

move, and I exist. You have given me the opportunity to occupy during my time here on

earth, to use my experiences in a way that will bring glory to Your name. I love, honor,

and appreciate You. I am always "watching the wind."

To my husband Dr. Shannon D. Jones, I love you! I fall more in love with you

every day! You have loved me through the good, the bad, and the ugly; and for that I am

grateful. I feel I am blessed to have someone at my side that understands the rigors of

completing a dissertation. Your love and support have carried me on days I could barely

stand on my own. In the dedication section of your dissertation, you indicated that you

"look forward to the day when we both call one another Doctor." You made that

statement knowing all of the labor, sacrifices, and tenacity required for completion. Well

the time is now, and I look forward to giving back to others all we have received.

To my beloved children, Shakora, Shannon II, and Dorian. Thank you for

understanding the need to sacrifice when there were five tuition payments in our

household (smile). You have lifted my spirits many days in our quality time together.

You have done an amazing job picking up extra chores since I began this project. I love

your humor, character, and passion for family. You have kept me sane. I would like to

thank my extended family and friends for your unconditional love and support.

To Dr. Kristin Haglund, my Dissertation Chair and mentor, what can I say that

would adequately define your worth to me? I can never fully express my gratitude to you

with mere words. You have encouraged, advocated, and shared your personal victories. You have exceeded your call of duty and have walked with me through the joys and complexities of pregnancy, obtaining my Masters degree, caretaking, loss, and some amazing milestones. Because of you I am inspired to embrace scholarship. Thank you for believing in me and enabling me to soar beyond measure. Your expertise with adolescents and qualitative methodology is admirable.

To Dr. Belknap, thank you for your insight and encouraging me to genuinely own this project. Your holistic approach to scholarship is respected. You are simply invaluable.

To Dr. Schaefer, thank you for your patience and gentle push for clarity of concepts that serve as a foundation for this project. Your mentoring has been an extraordinary blessing.

To Dr. Alexis Thompson, thank you for your mentoring and support of this project. To the Sickle Cell Disease Association of Illinois, thank you for your support. To Dr. Paul Scott, thank you for your assistance. To Brynnan Gilgour, Stephanie Pelligra, and Pauline Hess, thank you all for your assistance. To Dr. Margaret Bull, thank you for your mentoring and leadership. To Dr. Harold Koenig, Dr. Verna Benner-Carson, and Dr. Susan Ridgely, thank you for your insightful guidance on conducting research in my topic area and mentoring. To Holly Oxhandler, thank you for your thoughtful review of my interview guides. To Nia Feaster and Donovan Owens, thank you for serving as adolescent content reviewers.

To my dissertation support/writing group, Celeste Harvey, Felisa Parris, and Marnie VandenNoven, your encouragement is life changing! To the faculty and staff of

Marquette University, thank you for your assistance and inspiration.

I would like to thank the Arthur Schmitt Foundation, the Nurses Foundation of Wisconsin, and the Milwaukee District Nurses Association for your support and funding.

To all of the adolescents that participated in this study, thank you for taking time to share your voice to assist others in understanding the meaning of spirituality and religiosity for teens living with sickle cell disease.

I dedicate this Doctoral Dissertation to the loving memory of my GRANDmother Pauline Conway-Clayton. You taught me at an early age the power of maintaining vision for my life. Thank you for your sacrifices, advocacy, nurturing, and instilling values that will be passed on to future generations. Because of your love and example, I endeavor to be the best woman, wife, and mother I can be. Love you forever, "Lessie."

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

Introduction

Spiritual and religious practices of adolescents have been documented to influence coping with illnesses, health outcomes, and health care decisions. Advances have been made in research conducted with adults, exploring spirituality and religiosity in the context of health and illness. Few studies address spirituality and religiosity in the context of health and illness for adolescents.

Chapter one reviews the background, purpose, need for the study, and the significance of the problem. The background information provides a general description of sickle cell disease to include disease types, signs, and symptoms; the impact of sickle cell disease during adolescence; and clinical and supportive care interventions. Spirituality and religiosity as vital components of holistic care are described, followed by an introduction of the Spiritual Development Framework. This chapter will end with documentation of need, purpose of the current study, and the significance of the problem to nursing.

Background and Significance

Sickle cell disease (SCD) is a chronic and debilitating disease. The disease affects millions of individuals primarily living in Africa, East India, the Middle East, South and Central America, the Mediterranean, the Caribbean, and North America. Approximately five percent of the world's population carries trait genes for hemoglobin disorders, mainly SCD and thalassemia (World Health Organization, 2011). More than 300,000

babies with severe hemoglobin disorders are born each year worldwide (World Health Organization, 2011). An estimated 70,000 to 100,000 Americans of various ethnic backgrounds have SCD syndromes, although African Americans are most commonly affected. Sickle cell disease affects one in 500 African Americans in the US (National Heart, Lung, and Blood Institute, 2009). The financial strain the disease has on the family and health utilization in the US is significant. There are approximately 113,098 hospitalizations and more than one billion dollars in hospital costs attributed to SCD annually in the US (Steiner & Miller, 2006; Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). The hospital 30-day readmission rate for SCD is 31.9% and accounts for the highest readmission rate compared to all other diagnoses including heart failure or renal failure (Elixhauser & Steiner, 2013).

Description of Sickle Cell Disease

Sickle cell disease is an autosomal recessive genetic disorder that results in chronic anemia, pain, disability, organ damage, increased risk for infection, and early death (Ignatavicus & Workman, 2006). As a result of this genetic mutation, more than 50 percent of the total hemoglobin in the blood of an affected person contains an abnormality of the beta chains known as Hemoglobin S (HbS) (Bridges & Pearson, 2008). Unlike normal hemoglobin, HbS sticks together after giving up oxygen to the tissues. It is sensitive to the amount of oxygen in red blood cells (RBC). When RBCs with large amounts of HbS are exposed to decreased oxygen states, the cell membrane becomes distorted, leading to increased blood viscosity. These abnormal cells become sickle shaped, cluster together, and form masses of sickled RBCs that obstruct blood flow, particularly in the small capillaries. Obstruction of blood flow leads to problems

with circulation, including ischemia, hypoxia, infarction, and progressive organ damage. In addition, the lack of oxygen supplied to the body causes pain. Clients with SCD have episodic periods of extensive sickling called *crises*, which are described as excruciatingly painful.

The four most common SCD syndromes, listed in the order of greatest severity, include: Hemoglobin SS, Sickle β° thalassemia, Sickle β+ thalassemia, and Hemoglobin SC disease. The percent of HbS in each syndrome is 99%, 91%, 71%, and 53% respectively (Bridges & Pearson, 2008). Hemoglobin SS and Sickle β° are usually the most severe of the four syndromes and are associated with low hemoglobin values, painful crises, decreased life expectancy, and organ damage (Bridges & Pearson, 2008).

Sickle cell disease affects many systems, including cardiovascular, respiratory, digestive, lymphatic, endocrine, reproductive, urinary, integumentary, musculoskeletal, and the central nervous system (Pinckney & Stuart, 2004; Rees, Williams, & Gladwin, 2010; Weinblatt, 1998). Physical complications affecting the cardiovascular system include cardiac enlargement and systolic murmur. Acute chest syndrome, pneumonia, pulmonary infarct, and pulmonary hypertension may affect the respiratory system and are the most frequent causes of hospitalization in older adolescents (Rees, et al., 2010; Weinblat, 1998). Repeated pulmonary infarctions lead to pulmonary disease, compromising vital lung capacity and gas exchange over time (Weinblat, 1998).

Hepatomegaly and constipation are complications that may affect the digestive system. Splenic sequestration can affect the lymphatic system, and a splenectomy is needed in many cases. If patients experiencing splenic sequestration do not receive prompt assessment and treatment, death can occur (Reddin et al., 2011). Persons with

SCD have fewer RBCs, resulting in a lack of oxygen being delivered to cells throughout the body. The lack of oxygen, along with increased metabolic demands, may lead to delayed growth and sexual development (Bennett, 2011; Sarjeant & Serjeant, 2001). Nephropathy and priapism are complications of the urinary system. A complication for the integumentary system is skin ulcers.

Complications of the musculoskeletal system include osteomyelitis, and bone necrosis. Skeletal involvement is a frequent cause of pain resulting from sickling and infarction in the sinusoids of bone marrow and ischemia of bone and periosteum. Complications of the nervous system may include eye damage, cerebrovascular disease, and cognitive impairment. By the age of 45, 24 percent of SCD patients will experience a stroke (Verduzco & Nathan, 2009). The most common problem that patients experience is pain resulting from the ischemic tissue damage, which affects every system. Common locations of pain for adolescents include the lumbosacral spine, knee, shoulder, and thigh (McClish et al., 2009; Rees et al., 2010; Weinblat, 1998).

Impact of Sickle Cell Disease During Adolescence

Adolescents with SCD experience symptoms, treatments, and complications of their condition that hinder them in their physical, psychosocial, emotional, and academic functioning. Frequent hospitalizations are common for many adolescents living with SCD. During a time when adolescents are focusing on establishing a sense of identity, the limitations of the hospital environment can be challenging. The ability to participate in activities may be limited by physical symptoms and isolation due to hospitalizations and illness. The impact of SCD during adolescence will be reviewed, and include effects on physical and sexual development, activities and social interaction, emotional well-being,

and academic achievement.

Physical and Sexual Development

Adolescents with SCD are often shorter, weigh less, and have delayed sexual development in comparison to their peers (Bennett, 2011; Rhodes, Akoehouse, Shankar, Qi An, & Yu, 2009; Uchendu, Ikefuna, Nwokocha, & Emodi, 2010). Girls may be delayed in the onset of puberty and menarche when compared to their chronological age (Cepeda, Allen, Cepeda, & Yang, 2000). Boys are three times as likely to be underweight during adolescence compared to norms established by the Center for Disease Control (Mitchell et al., 2009). Compared to children without SCD (control) of similar race, gender, body size, and stage of puberty, 47% of control males and 86% of control females progressed from Tanner 2 to Tanner 4 stage of sexual development in a two-year period in comparison to 6% of males with SCD and 36% of females with SCD who progressed from Tanner 2 to Tanner 4 stage of development (Rhodes et al., 2009). Delayed physical development occurs only over a span of 10-15 years during the life cycle and is not permanent (Cepeda et al., 2000). With proper monitoring and interventions, adult size is generally in the average range.

Activities and Social Interaction

Hospitalizations and illness may often interrupt school and social life for adolescents with SCD (Suris, Michaud, & Viner, 2004). The American Academy of Pediatrics generally advises that if the condition of the illness permits, adolescents may play all sports except high exertion and contact sports (AAP, 1994; Pickney & Stuart, 2004). Activities that are physically demanding can result in a vaso-occlusive pain crisis

(Pickney & Stuart, 2004). Adolescents should be allowed to rest when tired and encouraged to drink fluids during and after exercise (Lane et al., 2002; U.S. Department of Health and Human Services, 2002). Attention and monitoring is required during all activities and light sports to avoid dehydration, overheating, extreme temperatures, and fatigue (Lane et al., 2002; U.S. Department of Health and Human Services, 2002). For adolescents with SCD, living as close to a normal life as possible with their peers is critical for development of peer relationships and self-esteem (Ladd, 1999).

Emotional Well-Being

Adolescents experience a number of fears and anxieties while coping with SCD, including fear of addiction to narcotics, fear of death, anxiety about becoming independent from adult caregivers, and anxiety about pregnancy and having their own children in the future (Dennis-Antwi, Culley, Hiles, & Dyson, 2011; Pickney & Stuart, 2004). Pain management for adolescents with SCD frequently incorporates administration of oral and intravenous narcotics such as codeine and morphine (Lane et al., 2002). Adolescents may be afraid and reluctant to request pain medication due to their perception that their requests will lead their health care providers to view them as being addicted to drugs (Labbé, Herbert, & Haynes, 2005). This fear or perception may lead to issues with trust and respect, causing adolescents with SCD to experience inappropriate pain management and inadequate pain control (Elander, Beach, & Haywood, 2011).

Adolescents with SCD become aware of the life-shortening nature of the disease. Some have a family member or friend who lived with SCD and experienced a shortened life span as a result of complications of the disease. In 1973, the average life expectancy

for persons with SCD was 14 years of age, with very few living to the age of 30 (Diggs, 1973). Currently the average life expectancy for persons with SCD is approximately 20-30 years less than for those without SCD (Center for Disease Control and Prevention, 2012). Parents purposely withhold information from their children to prevent them from being anxious and fearful about death (Newland, 2008).

Adolescents may experience an increase in the severity of their illness during puberty (Bridges & Person, 2008; Newland, 2008). This change in health status results in additional stress, emotional strain, and difficulties for adolescents and their families. With an increase in the severity or frequency of symptoms, loss of physical abilities, and fear of death, the future may appear bleak and uncertain.

Adolescents under the care of pediatric healthcare providers often have a greater sense of security (Newland, 2008; Pickney & Stuart, 2004). As adolescents transition from the care of a pediatric provider, they may not be prepared for the transition to adult care and the responsibility required during the transition process. Adolescents are often preoccupied with concerns associated with the transition process, which can be a source of stress for them long before reaching the age of 18. Young adults with SCD are at risk for early mortality (Quinn, Rogers, McCavit, & Buchanan, 2010). Factors that influence the health and mortality rates of young adults with SCD include limited access to private health insurance versus public health insurance, lack of insurance, lack of access to subspecialty care/availability of adult hematologists, and preparation for transitioning to adult care (DeBaun & Telfair, 2012; McPherson, Thaniel, & Minniti, 2009), Adolescents believe that few adult providers are specialized in the management of sickle cell disease and expressed being afraid of transitioning to adult care and of dying

(Newland, 2008).

Becoming pregnant and having children during adolescence causes anxiety and stress (Pickney & Stuart, 2004). The period of adolescence is not an optimal time for adding new members to a family. This is especially true for adolescents with SCD. There are risks and complications associated with pregnancy for adolescents with SCD (Obrien et al., 2011). While there are risks associated with pregnancy, the rate of pregnancy among adolescents with SCD is no lower than the general population of teens (Obrien, et al., 2011). The pregnancy may likely impose additional stress on the family by disrupting the current family structure, causing economic strain, and impacting the ability to secure educational and employment opportunities (Pickney & Stuart, 2004).

Academic Achievement

Hospitalization and illness may impact the ability of adolescents with SCD to attend school, keep up with peers academically, and impede attaining educational goals. Persons affected by SCD have increased rates of cognitive delays which may affect academic achievement. Cognitive delays are thought to result from abnormal patterns of brain maturation and strokes (Barden et al., 2000; DeBaun & Telfair, 2012; Puffer, Schatz, & Roberts, 2010; Sanchez, Schatz, & Roberts, 2010). Consideration of physical and psychosocial issues faced by adolescents with SCD may provide significant information for health care providers. Health care providers are in the position to provide support for adolescents with SCD to address their physical and psychosocial concerns.

Adolescents with SCD experience several developmental challenges. Concerns related to physical and sexual delays, participating in sports and activities, maintaining social interaction with peers, fear of academic failure, and fear of transitioning to adult

services are areas where assessment and intervention are essential. Adolescents are aware of the shortened life expectancy, which usually accompanies the disease, and may experience fear related to their life expectancy and the possibility of death. Realizing the incidence of a shortened life span may create a sense of hopelessness about the future.

Clinical and Supportive Management for SCD

The clinical and supportive management of patients with SCD is essential to the overall care for this population. Adolescents with SCD are evaluated on an ongoing basis with the frequency of follow-up visits being recommended by their health care provider and team. Management includes medical care and interventions, as well as ancillary care that provides resources and psychosocial support. The goals of medical management are to prevent and treat infections, manage vaso-occlusive crises, manage chronic pain and anemia, and prevent and manage complications.

Medication management includes specific supplements and medications to prevent infections, increase the production of fetal hemoglobin, and alleviate pain during a vaso-occlusive pain crisis. Folic acid is lost through damaged cells so supplementation is necessary. Administration of folic acid is especially important during periods of rapid growth, such as during adolescence. Zinc and iron may also need to be supplemented in order to support growth and development.

Providing prophylaxis against infection is critical as this is the most frequent cause of death for those living with SCD (Rees et al., 2010; Weinblat, 1998). For adolescents who have had their spleen removed, prophylactic antibiotics are taken indefinitely (Price, Blanchette, & Ford-Jones, 2007). Prescribing medications that increase the production of fetal hemoglobin (hemoglobin F) is another treatment option.

Fetal hemoglobin interferes with the formation of the sickle polymer (Wang et el., 2011; Weinblat, 1998). As fetal hemoglobin increases, the number of sickled cells in circulation decreases, as well as the potential for having vaso-occlusive crisis episodes.

Adequate management of vaso-occlusive pain crises is associated with increased life expectancy. The number of pain episodes and hospital readmissions after visiting the emergency department are associated with an increased risk of death in SCD patients (Reddin et al., 2011), thus emphasis needs to be placed on early assessment and prompt treatment of pain. Clinicians must take advantage of every opportunity to manage pain on an outpatient basis. Patients are treated with oral analgesics and narcotics depending on their pain severity. For pain that cannot be managed with oral medication, hospitalization for administration of intravenous non-steroidal anti-inflammatory agents and narcotics is necessary. A continuous morphine infusion, especially those with patient-controlled delivery, gives uninterrupted and effective pain relief.

Transfusion therapy is another approach for clinical management. Administration of packed red blood cells improves patients' oxygenation and causes hemodilution of cells containing sickle hemoglobin with hemoglobin A, suppression of new sickle hemoglobin, and decreased blood viscosity (Rees et al., 2010; Weinblat, 1998).

Hematopoietic stem cell transplantation is a treatment with curative potential for persons with homozygous SCD (Bridges & Pearson, 2008; Michlitsch & Walters, 2008). Hematopoietic stem cell transplantation is considered for patients with SCD who are 16 years of age or younger without extensive organ damage (Michlitsch & Walters, 2008). Transplantation involves administration of stem cells to the patient with SCD to restore hematopoietic function. Hematopoietic stem cell transplantation using bone marrow or

cord blood is a viable option for those meeting the criteria (Bridges & Pearson, 2008). The long-term effects of bone marrow transplantation continue to be researched for improvements in this approach to clinical management.

Education for both the patient and family is essential for supportive care. Teaching includes understanding SCD and its genetic basis, the importance of daily management, and recognizing the signs of a vaso-occlusive crisis. Providing information on the pathophysiology of SCD and avoidance of potential triggers for vaso-occlusive crises may be helpful in minimizing the effects of the disease (Bridges & Pearson, 2008; Serjeant & Serjeant, 2001). Reviewing the importance of medication adherence and identifying methods to encourage compliance is vital. Educating families and adolescents can empower them to provide and seek optimal health care. Education provides patients and families with valuable skills that can assist them in advocating for their health needs and obtaining relevant resources.

Holistic Care, Spirituality, and Religiosity

Holistic care encompasses the body, mind, and spirit of the human person. The nursing needs of individuals are determined using a holistic approach (American Nurses Association, 2010). Holistic nursing considers the interconnectedness of the body, mind, and spirit, and encompasses healing of the whole person (American Holistic Nurses Association, 2010). When discussing holistic care, defining concepts associated with the spiritual and religious characteristics of the person is important. The terms *spirituality* and *religiosity* have been used interchangeably in some literature, but each has a different meaning, which has significance for the current qualitative study. Thus, the definition of each concept is necessary to assure clarity and to demonstrate the connection between

them.

Scholars have noted various aspects of spirituality in conceptualizing this element of persons. Spirituality encompasses the human search for meaning in life. Meaning in life can be sought from intrapersonal, interpersonal, and transcendent connections (Reed, 1992; Watson, 2012). Meaning refers to the interpretation of an experience or experiences that structure life (Cacioppo, Hawkley, Rickett, & Masi, 2005). Spirituality surfaces as an innate element of being human that is individualistic, subjective, intangible, and multidimensional (Benner-Carson & Koenig, 2004; Koenig, 2001; Narayanasamy, 2004; Tanyi, 2002). Spirituality has been regarded as the essence of our being, and gives meaning and purpose to our lives (Koenig, 2007; Puchalski & Romer, 2000).

For the purpose of the current study, *spirituality* is defined as the innate capacity of human persons to transcend themselves to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003; Miller & Thoresen, 2003; Pargament, 1997).[1] *Sacred* refers to a divine being, or ultimate reality or ultimate truth as perceived by the person (Larson, Swyers, & McCullough, 1998). People can discover meaning and purpose through relationships and personal experiences (North American Nursing Diagnosis Association, 2001; Reed, 1992). Spirituality does not require adherence to a particular religious tradition.

[1] In constructing definitions of spirituality and religiosity, several references were reviewed. For a discussion of how doctors, nurses, chaplains, physical therapists, and other health professionals define spirituality and religiosity, see Benner-Carson & Koenig (2004, pp. 1-25). For a scientific review of current research in child and adolescent spiritual development, see Roehlkepartain, King, Wagener, & Benson (2006). For a discussion of nursing definitions of spirituality, aspects of spirituality, characteristics and

distinctions of related concepts, and manifestations of spirituality, see Taylor (2002, pp 3-20).

Methods for developing, reinforcing, and/or deepening a person's spirituality include intrapersonal, interpersonal, and transcendent connections (Reed, 1992). Intrapersonal connection refers to the internal aspects of the person and is often discussed in the context of relationship with oneself. Relationship focuses on a sense of connectedness with the inner self (Lowe, 2002; Rankin & DeLashmutt, 2006; Reed, 1992).

Intrapersonal connectedness may also include meditative practices. Meditation methods include mindfulness meditation, transcendental meditation, mindfulness-based stress reduction, and mindfulness-based cognitive therapy (Anderson & Liu, 2008; Barnes et al., 2004; Black et al., 2009; Goleman, 1998; Merkes, 2010, Umlauf, 1997). Meditation has been associated with improved health outcomes among children and adults (Anderson, Liu, & Kryscio, 2008; Barnes et al., 2004; Black et al., 2009; Delaney & Barrere, 2009; Merkes, 2010). Meditation can serve to alleviate stress and increase the ability to focus on a more positive outlook.

Interpersonal connectedness is associated with relationships between others. These connections would include the creative arts (art, music, dance, poetry, drawing, painting, writing, and sculpting) as a means of relatedness (Puchalski & Romer, 2000; Reed, 1992; Boyle, 2006). Through creative arts, people are able to express and develop their spirituality (Trousdale, Bach, & Willis, 2010). Art, music, dance, painting, writing, poetry, and sculpting may be used as methods for nonverbal and verbal expression and connectedness (Boyes, 2006; Lane, 2005). Through relationships, persons can experience a sense of connectedness, as well as derive a sense of meaning and purpose in their lives

(Cavendish et al., 2004; Sessanna, Finnell, & Jezewski, 2007).

Transpersonal connectedness encompasses relationship with the unseen, a higher being, the sacred, or an entity connected to a power greater than the self (Reed, 1992). Persons extend beyond ordinary resources to seek a purpose beyond themselves. Connectedness may be experienced through religion where one is able to find love or strength in their connection to a higher being (Fetzer Institute & National Institute on Aging Working Group, 2003). Desiring and experiencing a sense of unity with the sacred through practices, music, prayer, family, and other associations are all examples of transpersonal connectedness (Fetzer Institute & National Institute on Aging Working Group, 2003; Roehlkepartain, Benson, King, & Wagener 2006).

Religiosity may be understood as an orientation to a particular type of spirituality grounded in a specific religion wherein people share faith-based traditions of that religion, adhere to a set of beliefs that express that religious tradition, and engage in religious practices with one another. The religiosity of a person is likely to have a specific emphasis and is an approach for connecting with a higher being. For the purpose of the current qualitative study, the term *religiosity* is defined as a commitment to an organized way of knowing and orienting one's self to the religious community's subject of worship (Schaefer, 2010). Religion may be used by turning to a higher being for support during encounters perceived to be challenging. During the process of making a decision, persons may rely on their higher being and/or religious traditions for guidance, which might be positive or negative to their coping with an illness.

The spirituality and religiosity of adolescents are vital components of holistic care. Both components may be considered dynamic and protective factors that promote

positive health outcomes in adolescents. The spirituality and religiosity of adolescents

may influence their coping with illness, affect health outcomes, impact how patients and

their families make health care decisions, and influence health care in the community

(Cotton, Grossoehme, Rosenthal, McGrath, Roberts, Hines, & Tsevat, 2009; Cotton,

Zebracki, Rosenthal, Tsevat, & Drotar, 2006; George, Larson, Koenig, & McCullough,

2000; Harrison, et al., 2005; Jackson, et al., 2010; Kloosterhouse & Ames, 2002; Sibinga,

Shindell, Casella, Duggan, & Wilson, 2006; Wong, Rew, & Slaikeu, 2006). The

spirituality and religiosity of an adolescent can be interrupted during periods of illness.

Patients are often isolated from their religious communities when experiencing an illness

or hospitalization. Adult patients want health professionals to address their spiritual and

religious needs, but many providers do not focus on these elements (Koenig, 2007;

Puchalski & Romer, 2000). The situation may be worse for adolescents who have a desire

for their spiritual and religious needs to be addressed, but their needs are often unmet

(Moody et al., 2011; Zebrack et al., 2013). Lack of attention to spiritual and religious

needs may be attributed to the comfort level of the health provider, lack of time, amount

of training received related to spirituality and health care, uncertainty about how to attend

to these elements in a pluralistic health care setting, and the belief that the assessment and

intervention of these elements should be left to clergy (Boswell, Cannon, & Miller, 2013;

Gallison, Xu, Jurgens, and Boyle, 2013). Researchers suggest addressing the discomfort

experienced by health care providers by offering education to include an ongoing

evaluation of learning needs.

Researchers have shown that investigators have often assumed that adolescents do

not have religious beliefs or spiritual concerns that need to be addressed (Nabhan-

Warren, 2011; Pike, 2011). A comprehensive review of studies regarding spiritual

assessment in adolescents and what adolescents would like their health care providers to

address in relation to their spiritual and religious needs shows that little research has been

done to assess the spirituality and religiosity of adolescents (Cotton, Grossoehme,

Bignall, & Weekes-Canu, 2013). Literature addressing the spirituality and religiosity of

adolescents in the context of health and illness is also lacking. The current study explores

the spiritual and religious elements of adolescents living with a chronic illness, and may

enlighten health care providers on how to meet the holistic needs of teens. Holistic care

encompasses caring for the whole person, acknowledging an interconnection between the

body, mind, and spirit. The current study proposes to address gaps in the literature related

to caring for adolescents using a holistic approach. Health care providers may be

encouraged to seek methods that foster continued adolescent spiritual development, and

encourage integration of the patients' spirituality and religiosity within the health care

setting. Furthermore, providers may be stimulated to discern methods for providing

holistic care more effectively to adolescents and identifying practical interventions for

individualizing their care. Awareness of all elements of human development for

adolescents with SCD is essential for their optimal treatment.

Introduction of the Spiritual Development Framework

The Spiritual Development Framework developed by Benson & Roehlkepartain

(2008) provides a basis for conceptualizing the spiritual element of human development.

The framework was chosen as the conceptual framework for the current study to provide

direction in considering spiritual development in adolescents living with a diagnosis of

sickle cell disease. Consideration of spiritual development in the context of health and

illness will identify methods to improve the well-being of adolescents. Discussed fully in the next chapter, the framework allows for consideration of factors involved with the process of spiritual development. Religiosity is a type of spirituality grounded in a particular religion. Religiosity can inform an individual's spirituality. Understanding spiritual development can provide insight on the connection of meaning and purpose to health outcomes.

Documentation of Need

For years there were no designated centers where health providers could assess and focus on health issues and major areas of concern for the SCD population. Care was uncoordinated and patients experienced a lack of health care advocacy. In the US, it was not until the 1970s that federal legislation was passed to develop specialized SCD centers (Woods & Ballas, 2006). Specialized care in dedicated centers, however, is still not available in most countries where SCD is a major health concern (World Health Organization, 2006). Despite progression in legislation for SCD management, disparities persist in the US, as in other nations, related to government and charitable financial support for research and treatment (Smith, Oyeku, Horner, & Zuckerman, 2004). Supportive and self-care practices may improve management of the illness and avoid exacerbations, but there is no widely available cure. The complexity of SCD and critical need for consistent and coordinated care necessitates ongoing evaluation and provision of comprehensive support.

The study of spirituality and religiosity and its relevance to health and illness has been documented in nursing literature. However, how adolescents with SCD describe their spirituality and religiosity and the significance these elements have in their lives has

not been studied exclusively.

Understanding how adolescents describe and experience their spirituality and religiosity is critical in designing care and follow-up interventions tailored for them. Gaining this understanding may help health providers plan not only for the spiritual needs of adolescents who are experiencing chronic illness but also provide information that will support the development of interventions appropriate for use across the lifespan.

Investigating spirituality and religiosity may identify significant considerations and ways to work more effectively with adolescents who have SCD. Helping adolescents understand the elements of spirituality and religiosity may be an effective intervention to improve management of SCD, improve health outcomes, and reduce the burden of problematic symptoms of SCD. Within Eastern, African, and Native American cultures, spiritual and religious beliefs are critical to care and often integrated when addressing issues related to health (Watson, 2012; Walker, 2005). Conversely in Western models of health care, spirituality and religiosity are routinely neglected when working with individuals and their families (Rousseau, 2003; Umlauf, 1997). This neglect may be to the patients' detriment because spirituality and religiosity are important elements of life for many, and influence their perspectives on their health and well-being, managing illness, choices regarding health care utilization, and self-care practices (Naraynasamy, 2004; Puchalski & Romer, 2000).

Medical care advances in SCD have focused primarily on the physical elements of the illnesses. The foci of the current study are the spiritual and religious elements of the person. Results of the current study will contribute to the body of knowledge about the significance of spirituality and religiosity to adolescents, raise the consciousness of health

care providers, and provide guidance in conducting comprehensive assessments to include spirituality and religiosity in adolescents with SCD. The current study will lay the groundwork for further research and intervention development on spirituality and religiosity in teens.

Purpose of Study

The purpose of the current study was to examine how adolescents with sickle cell disease describe and experience their spirituality and religiosity. Because the aim of providing holistic care is to encompass all elements of the human person, the adolescent's spirit must also be encompassed with the body and the mind. The current study addressed the spiritual and religious elements of the human person for the purpose of offering health care providers an understanding of the experiences of adolescents from their perspective. Awareness of their spirituality and religiosity will position nurses to develop meaningful individualized interventions in order to meet the spiritual and religious needs of their patients, provide support for them, and promote their overall health and well-being. The specific aims of the current descriptive qualitative study include:

(1) Examine how adolescents living with sickle cell disease describe their spirituality and religiosity.

(2) Examine the process of spiritual and religious development in adolescents with sickle cell disease.

(3) Examine the role of spirituality and religiosity in shaping beliefs about health and illness for adolescents with sickle cell disease.

(4) Provide adolescents with sickle cell disease a voice in describing their

experiences of spirituality and religiosity.

There are three main areas indicating the current study is significant for nursing to

include: nursing practice, nursing education, and nursing research.

Significance to Nursing Practice

Providing holistic care is a central theme in nursing practice. Nurses are

recognized for meeting the diverse needs of their patients. By nurses acknowledging the

spiritual and religious elements of their patients, those patients' spiritual and religious

needs are more likely to be assessed and met. This may assist in preventing or curtailing

experiences of spiritual distress.

Including aspects of patients' spiritual and religious belief system when

developing interventions allows for integration of patient-centered care. This level of care

will likely lead to better patient outcomes (Benner-Carson & Koenig, 2004; Koenig,

2007). Due to developments in technology, patients are living longer. Technological

advances do not necessarily match arising needs resulting from these advances. Being

leaders in providing spiritual care will keep nurses at the forefront of delivering care that

keeps up with the pace of advances in technology by meeting individual holistic needs.

Completing a holistic assessment to include a spiritual assessment can assist in

addressing the spiritual and religious needs of adolescents. A holistic assessment may

provide health care providers with an improved understanding of this population as well

as an awareness of approaches that can be used to improve health outcomes. Spirituality

has been considered a universal phenomenon and significant across the lifespan (Benson

& Roehlkepartain, 2008; Puchalski & Romer, 2000). Addressing this element of all

persons including adolescents is, therefore, essential.

Adolescence is a unique period of development during the life cycle. When addressing spirituality and religiosity of adolescents, providers may lack direction on how to assess and integrate these elements of the person into the plan of care. Little attention has been given to spiritual development in health care. Assessment of spirituality and religiosity for patients is critical in providing holistic care. Further exploration into these elements of adolescents can provide health care providers with insight about how to integrate the spiritual and religious needs of adolescents into the plan of care.

Significance to Nursing Education

Nursing education supports provision of comprehensive nursing care. As nursing educators embrace holistic care, this can make a significant contribution toward successful integration of spirituality concepts in the nursing curriculum.

Based on a study exploring students' perceptions of providing holistic care, students were generally not comfortable providing holistic care to patients. Students were enrolled in a nursing course that incorporated spirituality (Boswell et al., 2013). Through a journaling exercise, students expressed some level of discomfort regarding the concept of spiritual care and related concepts. Interpretation of study findings indicated that for students participating in the course, there was a need for additional education on spirituality. This reinforces that to assume any level of competency in holistic care, ongoing education and training are essential. In another study that explored how undergraduate nursing instructors instructed nursing students on spiritual care, a main concern was facilitating student awareness of providing spiritual care (Cone & Giske, 2013). The authors also posit that having an awareness of holistic care concepts,

addressing barriers, and guided support can all assist nurses in becoming competent in providers of holistic care.

Significance to Nursing Research

Adolescents are often at risk for detrimental behavioral and health outcomes as a result of poverty and poor access to necessary resources (Girard, 2009; Males, 2009). Unfavorable outcomes can often be greater for adolescents living with a chronic illness (Hendricks-Ferguson, 2008; Snethen, Broome, Kelber, & Warady, 2004). Research addressing spirituality and religiosity for adolescents living with SCD demonstrated a relationship between religiosity and improved health outcomes (Anie, Stepsoe, Ball, Dick, M. & Smalling, 2002; Cotton et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). Further exploration into this relationship by gauging the influence of spirituality and religiosity in the context of health and illness for adolescents with SCD can increase and strengthen the knowledge nurses need to care for their patients. The study of the relationship of spirituality and religiosity on health outcomes for adolescents with SCD is limited. Spirituality and religiosity are salient elements of life for many adolescents. Understanding the influence these elements of the person have on health and illness informs health care providers. Individualized interventions developed with consideration of spiritual preferences and concerns are lacking.

Knowledge gained from research will increase awareness, promote dialogue between nurses and their adolescent patients, and encourage providers to resist assumptions regarding the spiritual and religious needs of teens. This current research will also contribute to the capacity of addressing the health needs of adolescents that may intersect with their spiritual and religious beliefs. Because the spiritual and religious

needs of adolescents living with SCD may change during the course of the disease, the spiritual and religious transitions adolescents encounter during the course of the disease will not be recognized if nurses are not sufficiently informed. Expanding the knowledge of nurses will likely promote the incorporation of holistic assessments of adolescents in their health care plans. Holistic assessments that include the spiritual element of adolescents will aid in developing holistic interventions reflective of their spiritual and religious needs.

Nurses embrace the concept of holistic care, viewing mind, body, and spirit as a whole when conducting assessments and creating individualized holistic care plans. While the concept is embraced, the actual practice of holistic care appears to be minimally oriented toward the spiritual and religious elements of adolescent patients. Further examination of these elements may provide information from a health care perspective that can lead to their practical integration in caring for adolescent patients, thus supporting the delivery of holistic care.

Research addressing the relevance of adolescent spirituality and religiosity to the health and illness of this population in general is limited. Nursing research addressing the spiritual and religious needs of adolescents is also limited. Health care providers from other disciplines have expressed interest in this vital area of research. Designing research studies that include spirituality and religiosity in the context of health and illness for adolescents can advance nursing as a profession, empowering nurses to be leaders in providing holistic care. The outcomes of the research can improve the provision of holistic care and impact the delivery of health care across disciplines. Collaborating with health care providers on research activities that incorporate spirituality and religiosity can

promote a flourishing multidisciplinary network for all health care providers. Nurses are positioned to advocate for the inclusion and consideration of spirituality and religiosity in the nursing curriculum and delivery of patient care.

CHAPTER TWO

Conceptual Framework and Review of the Literature

Chapter two includes a discussion of the conceptual framework that supports the current study, a review of the literature, adolescents and vulnerable population considerations, a statement of the assumptions for the current study, and research questions the current study proposes to address. Chapter two is divided into two main sections: (1) philosophical and theoretical underpinnings, and (2) literature review. Spirituality and religiosity in adolescents as an age specific population is provided. A section is presented providing information on spirituality, religiosity, and health in adolescents and adults, followed by a discussion of psychoneuroimmunology and coping. Psychoneuroimmunology is a mechanism through which spirituality and religiosity likely exert physiological effects on the body, and influence or change the course of a chronic illness. Next, a section on the connection between spirituality, religiosity, and coping will be presented. Due to scarcity of literature addressing the adolescent population exclusively, research addressing adults with SCD ages 18 and over is incorporated with the aim of identifying additional information regarding the role of spirituality and religiosity in managing SCD. A summary of the literature to include: how the information is relevant to the current study; and gaps in the literature the current study proposes to support is provided.

Section One: Philosophical and Theoretical Underpinnings

Philosophical Underpinnings: Constructivist-Interpretive

Qualitative research is an activity that positions the researcher in the world of participants (Denzin & Lincoln, 2011). The qualitative researcher is interested in the perspectives of the participants, and seeks to understand how participants describe and make sense of their experiences (Maxwell, 2005). Qualitative research allows the researcher to be immersed in the setting of the participants. The constructivist-interpretive paradigm is one of the major models structuring qualitative research and provides the philosophical basis for the current study.

In order to provide an overview of the constructivist-interpretive paradigm, some of the major tenets are provided. The principles of the constructivist-interpretive paradigm include basic viewpoints on the ontology, epistemology, and methodology. The ontology addresses the nature of reality. Within the constructivist-interpretive paradigm, reality is relative in that it is dependent on the individual's experiences (Guba, 1996). Reality is subjective and consists of meaningful socially and experientially influenced constructions (Guba & Lincoln, 1994; Hesse-Biber & Leavy, 2006). For the current study, the researcher's intent is to gain an understanding of the participants' experiences and construct knowledge that reflects the participants' reality. The experiences of adolescents with SCD will be described from their perspectives during the interviews.

Epistemology is the theory of knowledge that questions how we know what we know (Creswell, 2007). The epistemology focuses on how participants interact with the environment (Creswell, 2007). How participants interact with the environment

determines how meaning is created. The experiences of the participants inevitably shape who they are and, therefore, shapes the data that is generated during the interview process. The data obtained will create new knowledge for the researcher and the participants. The new knowledge can be used to produce an improved understanding of the experiences of adolescents with SCD and further insight into how health providers can support this population.

The methodology refers to the procedure for conducting research and how the researcher seeks new knowledge (Creswell, 2007). The researcher incorporates the processes of hermeneutics and dialectics when conducting research. Hermeneutics is the process of interpreting and explaining collected data (Guba, 1996). Dialectics is a collaborative and reflexive process between the researcher and the participant where both are engaged in dialogue during the data collection and analysis process (Guba, 1996). Data provided by the participants during the interview process was interpreted and clarified by both the researcher and the participants.

In the current study, the constructivist-interpretive paradigm guides research by focusing on the concept that adolescents with SCD have unique experiences in comparison to other adolescents living with a chronic illness. The interpretation and views of the participants' experiences may differ from what may be reported if parents alone are queried. Obtaining reports directly from adolescents about their experiences will likely lessen the possibility of misinterpretation, which can occur with parent reports.

Conducting interviews will allow the researcher to obtain a descriptive picture of participants' experiences and the meaning making processes associated with those experiences. The interviews will also allow time for additional probing to more

completely describe experiences that surveys may not capture. Semi-structured interviews provide the interviewer and respondent with co-equal roles as both engage in a conversation of listening and asking questions regarding mutually relevant issues (Denzin & Lincoln, 1998). The interview serves as a potential driving force for social change. In the case of the current research, change reflective of spiritual and religious considerations for adolescents living with SCD are considered.

New knowledge and information about this population will be generated and imparted to contribute to understanding beliefs of participants, and how their beliefs intersect with their perspectives of health and illness. Individualized plans of care will reflect the spiritual and religious aspect of adolescents and assist in providing culturally congruent care.

Theoretical Framework: Spiritual Development Framework

A definition of spiritual development will be provided as a basis for the theoretical framework and to support consistency in terms for continuous discussion. Spiritual development will be described and distinguished from religious development. A description of the Spiritual Development Framework will be given, as it provides the fundamental theoretical structure for the current study. Concepts within the Spiritual Development Framework will be summarized. The relationship between concepts will be described.

Spiritual development is the process of growing the innate human capacity for self-transcendence leading the person to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003; Miller & Thoresen,

2003; Pargament, 1997). The manner in which one relates to the subject may include the sacred or non-sacred ways of life. Spiritual development embraces inner experiences to include the infinite or invisible and outer experiences expressed in daily activities, relationships, and actions. Spiritual development may or may not be grounded in a particular religious faith and drives the search for connectedness, meaning, and purpose in life (Benson et al., 2003). *Religious development* is the process of meeting the goals of an institutionalized religion and balancing this with personal religious ideas and concepts to include actions, rituals, and thoughts (Hay, Reich, & Utsch, 2006).

The Spiritual Development Framework developed by Benson & Roehlkepartain (2008) provides a foundation for conceptualizing the spiritual element of human development. The framework is presented in Figure 1. The framework was chosen for the current study as it provides a guiding approach to view spiritual development along with the consideration of factors involved with the process. The framework was designed recognizing that spiritual development can contribute to the health and well-being of others or contribute to their detriment. Consideration of spiritual development in the context of health and illness will identify methods to improve the well-being of adolescents.

Practitioners and providers working with adolescents generally receive training related to human development. This training is used as a foundation to assist with the assessment of issues faced by adolescents and the development of interventions to promote growth. The role of spirituality in development is not routinely included in the education and training of youth providers and practitioners. The framework focuses on the manner in which spiritual development occurs with consideration of interrelated

concepts. The framework is not grounded in stage theory, and age is not applied to determine or understand spiritual development. The framework is not hierarchical, but provides an approach and helpful descriptions for understanding the processes of spiritual development. The framework allows interpretations of spiritual development to remain open to variations in human experiences and the processes that evolve with those experiences. For the current study, the framework reinforces spiritual development, is a dynamic process, and takes into account cultural and individual variances. Inner experiences along with the daily activities of one's outward journey both impact spiritual development.

An aim of the current qualitative study is to examine the process of spiritual and religious development in adolescents with sickle cell disease. The framework is used to explore the processes of spiritual development of the participants in the current study. The framework provides direction for considering key developmental processes, other dimensions of development, and components of spiritual development. A second aim of the current study is to examine the role of spirituality and religiosity in shaping beliefs about health and illness for adolescents with SCD. The framework incorporates health outcomes resulting from the interactions between processes and interrelated concepts. The framework is an emerging framework. Scholars continue to seek to understand how spiritual development interacts with other dimensions of development.

Figure 1. Spiritual Development Framework

Components and Definitions of Theoretical Framework

According to the framework three central developmental processes undergird spiritual development. Each process varies in how it occurs for different people. The processes are (a) Awareness or Awakening, (b) Interconnecting and Belonging, and (c) A Way of Living (Figure 1) (Benson & Roehlkepartain, 2008). The authors posit that the processes are vital for healthy development. Further these processes are of interest to those engaged in spiritual and religious traditions around the world. Each process is embedded in, and interacts with, (d) Other Dimensions of Development (physical, cognitive, social, emotional, and moral), as well as (e) Social Contexts, (f) Culture, (g) Meta-Narratives, and (h) Change: Time/ Growth/ Significant Life Experiences) (Figure 1) (Benson & Roehlkepartain, 2008). The processes lead to (i) outcomes which may be harmful or healthy. Outcomes may be physical, cognitive, affective, or social.

Awareness

The three processes within the framework interact with each other and operate across the life span. Youth engage with each process in different ways and with varied levels of intensity. The processes may be experienced independently and in various orders. The first, *Awareness or Awakening,* is the act of being aware of one's self, others, and the universe in ways that nurture and develop meaning and a sense of identity (Benson & Roehlkepartain, 2008). This act consists of finding, accepting, creating, or experiencing a reason for being, or a sense of meaning and purpose (Benson & Roehlkepartain, 2008). An awareness of self indicates having clear insight about individual beliefs, thoughts, feelings, actions, and motivation. This consciousness of

individual characteristics and assets provides one with the ability to see the self as part of something greater. Awareness of others refers to having an appreciation for the beliefs, thoughts, feelings, actions, and motivation of others. Awareness of self assists in developing an awareness of others. Awareness of the universe may include the sacred, which may also be referred to as the divine or a transcendent force. Awareness of the sacred may include experiences of enlightenment, awakening, liberation, salvation, or other experiences (Roehlkepartain, Benson, & Scales, 2011). While fulfilling their quest for understanding, beliefs may develop about health and illness, as well as beliefs on the topics of life and death (Roehlkepartain et al., 2011). Awareness may be influenced by religiosity, as religious traditions and beliefs often shape worldviews. The views formed may address questions about life.

Interconnecting and Belonging

Interconnecting and Belonging is the process of experiencing significance in life events and relationships with others, the natural world, and a divine or transcendent force (Benson & Roehlkepartain, 2008). *Interconnecting* is finding, accepting, or creating profound significance and meaning in everyday experiences and relationships (Benson & Roehlkepartain, 2008). Through this process the person may experience a sense of love or responsibility for others and the world (Benson & Roehlkepartain, 2008). The person becomes connected to certain beliefs, traditions, mentors, communities, and narratives; these remain significant over time and may create a sense of belonging (Benson & Roehlkepartain, 2008).

A Way of Living

The process of *A Way of Living* is the expression of one's identity through action and relationships with self, others, the universe, and the sacred (Benson & Roehlkepartain, 2008). One's beliefs, values, and commitments are expressed and lived out daily and life is grounded in a sense of hope and belief. There may be experiences of hope, meaning, or resilience in the midst of hardship, conflict, and suffering (Benson & Roehlkepartain, 2008). The person contemplates spiritual challenges and questions and identifies ways to live a life of strength (Benson & Roehlkepartain, 2008). Each process interacts with additional components of spiritual development to include other dimensions of development, social context, culture, meta-narratives, and change.

Other Dimensions of Development and Interrelated Concepts

The concept (d) *Other Dimensions of Development* include physical, cognitive, social, emotional, and moral development (Benson & Roehlkepartain, 2008). Each dimension of development should be taken into consideration due to the various possibilities of interrelatedness with spiritual development. The focus of the framework is not how far along the process persons travel or if they are re-engaging in a particular area of the process, but what providers can learn by understanding where individuals are spiritually. Providers can begin to interpret if and how spirituality and religion are used by adolescents in managing their illness. More importantly, the manner in which spiritual development happens is the focus of the framework.

Social Contexts

Interrelated concepts are social contexts, culture, meta-narratives, and change. The concept (e) *Social Contexts* refers to the various environments individuals interact with generating different experiences (Benson & Roehlkepartain, 2008). Social settings for individuals include family, peers, and community. Family has impact on the spiritual development of youth. For example, in a national study of 7,618 young people from eight countries, nearly one-half of participants identified that their family provided the single greatest influence in their spiritual lives (Roehlkepartain, Benson, Scales, Kimball, & King, 2008). Peers can support adolescent spirituality and development and spirituality can, in turn, support peer relationships (Schwartz, Bukowski, & Aoki, 2006). The values, beliefs, and practices of community may originate from congregations, neighborhoods, schools, youth development organizations, and other groups (Benson & Roehlkepartain, 2008). The involvement of social contexts is a consideration when examining spiritual development. Spiritual development will vary with experiences and contexts. Being aware of social contexts prompts health care providers to remember that adolescents are part of a larger community that may view the world in distinctly different ways than health care providers.

Culture

The concept (f) *Culture* refers to the shared language, customs, norms, and symbols that individuals identify with in a larger group (Benson & Roehlkepartain, 2008). Culture is influenced by existing sociopolitical phenomena. Culture is not dealt with from just an intellectual perspective, but takes into consideration sociopolitical

phenomena such as discrimination, oppression, and racism. Adolescents may participate in more than one culture or tradition at a time (Roehlkepartain et al., 2008). Their level of participation and significance attributed to their culture may shape their processes of spiritual development.

Meta-Narratives

Within the framework, (g) *Meta-Narratives* are described as the comprehensive explanations of history or knowledge that individuals or groups embrace. Meta-Narratives may include comprehensive descriptions of stories, scriptures, or myths. These comprehensive explanations of experience or knowledge may encompass religious traditions, political narratives, and philosophical narratives (Benson & Roehlkepartain, 2008).

Change

The concept (h) *Change* encompasses time, growth, and experiences that may interact with and influence each process of spiritual development. Moments in time can affect the course of persons' lives and their development. Spiritual growth influences how adolescents navigate through their experiences with consideration of all aforementioned framework concepts. Experiences of change have an influence on spiritual development and identity and are important considerations when examining spiritual development in adolescents (Benson & Roehlkepartain, 2008).

Outcomes

The processes of (a) *Awareness or Awakening*, (b) *Interconnecting and Belonging,* and (c) *A Way of Living* result in specific outcomes. The (i) *Outcomes* are the

healthy or unhealthy manifestations of the cognitive, affective, physical, and social effects of the interaction of the framework processes and the related components (Benson & Roehlkepartain, 2008).

Within the framework, spiritual development is considered a natural process for all people. While religion, along with related beliefs and practices, may be a connected component of spiritual development, spiritual development does not require religion in order to proceed. The framework suggests that the manner in which adolescents live through each of the three processes may differ from one another and depends on the other domains of development, related concepts, and their experiences. While the exact pathways of development may differ, adolescents may experience and arrive at comparable patterns of change and growth (Sroufe, 1997).

In chapter one spirituality and religiosity were defined. *Spirituality* is defined as the innate capacity of human persons to transcend themselves to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred. *Religiosity* is defined as a commitment to an organized way of knowing and orienting one's self to the religious community's subject of worship (Schaefer, 2010). Religion can inform and shape spiritual development. Through social contexts, culture, and narratives, the core processes of the framework may be influenced by religious beliefs and traditions. Spirituality encompasses the core processes of the framework. Through spirituality the identity of adolescents is molded, and they may discover their purpose. Social contexts, culture, and narratives may influence spirituality and spiritual development. Spiritual development does not require religiosity in order to transpire.

Development occurs over time, and each adolescent is unique in how he or she responds to life experiences and events. Spirituality and religiosity are influenced by the development and life experiences of the person. In the current study, adolescents with SCD describe their development and life experiences pertaining to their spirituality and religiosity. The framework provides an apriori understanding that the adolescents' processes of awareness (being aware of one's strength), interconnecting through relationships (experiencing significance in relationships), and a way of living (life grounded in purpose and meaning) will inform their understanding, interpretation, and narration of their experiences. The framework was used as a reference for reflection throughout the interview process. The framework provided an approach to view spiritual development and focus on processes and concepts that can be considered as being relative or significant.

Section Two: Literature Review

This section will present a review of the literature on the topic of spirituality and religiosity in adolescents, spirituality and health, spirituality and religiosity in adolescents with SCD, adolescents and vulnerable population considerations, a statement of the assumptions, and research questions the current study proposes to address.

Spirituality and Religiosity in Adolescents

There has been an increase among scholars in addressing the relationship of spirituality, religiosity, and spiritual development in children and adolescents (Benson, et al., 2003; Benson & Roehlkepartain, 2008; Petersen, 2008; Quinn, 2008; Regnerus &

Burdette, 2006; Regenerus & Uecker 2006; Smith & Lundquist-Denton, 2005;

Trinitapoli, 2007; Wilson & Nicholson, 2008). Spirituality and religiosity are integral

components of adolescent development. Spiritual development occurs in all adolescents

regardless of religious background and beliefs (Benson, & Roehlkepartain, 2008; Hay &

Nye, 2006). Incorporating spirituality and religiosity into theories, research, policies, and

practice is vital for having a positive impact on youth in various settings and to advance

the knowledge of disciplines interested in adolescent development (Benson &

Roehlkepartain, 2008; Petersen, 2008). Neglecting the spiritual element of growth can

impede healthy spiritual development.

Religious beliefs and routines are common among adolescents. The National

Study of Youth and Religion (Denton, Pearce & Smith, 2008) is a project that was

designed to improve understanding of the religious lives of American youth from

adolescence to young adulthood (Denton et al., 2008). This study consisted of a national

telephone survey of American youth and their parents in 2002-2003 and follow-up

surveys with the original youth participants in 2005 and 2007-2008. Personal in-depth

interviews were conducted with a subsample of youth surveyed in 2003, 2005, and 2008.

More than 2,500 adolescents aged 13-17 years completed this national longitudinal

survey about religion and beliefs carried out in two waves. During the 2002-2003 year,

84% replied "yes" to having a belief in God. When the same group of adolescents was

polled in 2005, 78% replied "yes" to having a belief in God. More than 60% of the

adolescents in the survey viewed the character of God as personal and more than 70%

attended religious services.

"Add Health" was a school-based longitudinal study of a nationally-representative

sample of adolescents (Harris et al., 2003). Adolescents in grades 7 through 12 from 132 schools participated in the study. The first wave of the study, Wave I, was conducted in 1994 and 1995. The majority of adolescents (nearly 77%) reported religion as being "fairly" or "very" important to them. Approximately 42% of adolescents prayed daily, approximately 38% attended religious services once a week or more, and 19% attended religious services once a month or more.

"Monitoring The Future" is an ongoing study of behaviors, attitudes, and values. A nationally representative cross-sectional survey of 12th grade students is conducted annually. In 2010 nearly one-third (30.3%) of participants reported attending religious services once a week or more and 54% reported religion as being "pretty important" or "very important" in their lives (Bachman, Johnston, & O'Malley, 2011).

Results of these large nationally representative studies indicate that spiritual and religious experiences are common for adolescents in the United States. These results support that the spiritual and religious involvement of adolescents should be taken into consideration by health care providers. Spiritual development is sometimes suppressed as a result of constraints within the social environment (Hay & Nye, 2006). This would include the health care environment. Gaining a greater understanding of spiritual and religious needs may support continued spiritual development in the health care setting and minimize the stifling of spiritual and religious growth.

Spirituality, Religiosity, and Health

Spirituality and religiosity in relation to health has received increased attention over the past 10 years due in part to policy statements about spiritual care and discussions within professional organizations. The Joint Commission for the Accreditation of

Hospital Organizations (JCAHO) encourages health care providers to respect patients'

spiritual and religious beliefs. Examples of suggestions for spiritual assessment questions

are provided on the organization's website (JCAHO, 2008). When providing palliative

care, health care providers are encouraged to respect the patients' beliefs and to attend to

their spiritual needs throughout the continuum of the illness (JCAHO, 2011). Contained

within the Code of Ethics for nurses is a statement that addresses meeting the spiritual

needs of clients and maximizing their spiritual well-being (American Nurses Association,

2010).

Spirituality, Religiosity, and Health in Adults

Research examining religion, spirituality, and health in adolescents is limited,

therefore research conducted with adults (to include older adolescents aged 18-21 years)

will be included for comparison. Results from the research have demonstrated that

spiritual and religious beliefs are used to manage living with an illness and have

significance for health care utilization and improved health outcomes in the adult

population (Berntson, Norman, Hawkley, & Cacioppo, 2008; Enstrom & Breslow, 2008;

Koenig, George, Titus, & Meador, 2004). In a quantitative study of patients 50 years or

older (N=811), organized religious activity was related to fewer acute care hospitalization

days and fewer hospitalizations during an average 21-month observation period (Koenig

et al., 2004).

A second quantitative study examined the relationship between spirituality and

patterns of cardiac autonomic control. Spirituality was directly related to parasympathetic

cardiac control (Berntson et al., 2008). Parasympathetic cardiac autonomic control is a

protective feature of the nervous system in that it acts on heart rate variability to control

heart rate and protect the heart from instability and damage. Parasympathetic cardiac control is directly related to a decreased occurrence of myocardial infarction and considered to have health significance. In a representative sample ($N = 229$), a high level of cardiac autonomic control was negatively associated with the occurrence of myocardial infarction ($r = -0.14$, $p = 0.04$). Spiritual and religious practices were directly related to greater parasympathetic cardiac autonomic control and inversely related to the occurrence of myocardial infarction (r [226] $= -0.14$, $p = 0.004$). Spiritual and religious practices were protective against damaging outcomes for the heart.

A third quantitative study measured the relationship of characteristics of the Mormon lifestyle to mortality. Several characteristics of the Mormon lifestyle were supported by their religion. Church attendance at least once a week, never smoked cigarettes, marriage, and at least 12 years of education were associated with increased life expectancy (Enstrom & Breslow, 2008). Life expectancy was 84 years for males and 86 for females ($N = 15,832$).

Chronic illness populations that have been studied in adults include those who have experienced a diagnosis of cancer, chronic pain, sickle cell disease, spinal cord injury, and stroke (Berges, Kuo, Markides, & Ottenbacher, 2007; Hampton, Hollis, Lloyd, Taylor, McMillan, & 2007; Marini & Glover-Graf, 2011; O'Connell-Edwards et al., 2009; Rippentrop, Altmaier, Chen, Found, & Keffala, 2005). Spirituality and religiosity has relevance for health outcomes (Berges et al., 2007; Rippentrop et al., 2005). Frequent attendance at religious services in adults 64 years of age and older ($N = 3,050$), pre-stroke was related to fewer declines in lower body functioning and improved physical function post-stroke (Berges et al., 2007). In a quantitative study examining

adult patients experiencing chronic musculoskeletal pain ($N = 157$), those with poorer health status had a higher frequency of private religious practices (Rippentrop et al., 2005). Spirituality and religiosity were associated with better mental well-being ($p=.032$). Study results suggest that religiosity may be a source of coping and assist in managing chronic pain.

Use of spirituality and religiosity as a means for coping was evident in another quantitative cross-sectional study of adult patients diagnosed with spinal cord injury ($N=157$). In this study, survey results indicated that spiritual and religious practices were found to assist in coping with illness, finding meaning in their lives, and were a source of happiness (Marini & Glover-Graf, 2011). For adult patients with advanced cancer and newly admitted to hospice home care ($N= 90$), addressing spiritual needs was significant (Hampton et al., 2007). Patients completed a spiritual needs inventory and prayer was cited as a frequent spiritual need for half of participants and being with family was a need cited by most participants (90%). Not being able to attend religious services was identified as an unmet need for 19 patients.

Spirituality and religiosity were associated with a healthier lifestyle, fewer hospitalizations, increased coping, and decreased occurrences of myocardial infarction in adults. Spiritual and religious activity were considered to be directly related to protective health factors and health outcomes. The frequency of religious attendance was related to improved physical functioning in adults post-stroke. The authors consider the influence of social networks on support and recovery (Berges et al., 2007). Another consideration is the impact of spiritual and religious practices on health maintenance pre-stroke, and how this may impact recovery. A third consideration is the association of chronic illness with

frequency of spiritual and religious practices.

Spiritual care and patient preferences are important for health care providers to consider. Adults are primarily used as a frame of reference in presenting reasons for spiritual care integration, but similar basis for integration also applies to adolescents. Adolescents are likely to follow the spiritual and religious beliefs and practices of their parents or other adults (Schwadel 2008; Smith & Lundquist-Denton, 2005; Woodgate & Degner, 2003). The spiritual and religious beliefs and practices of the family should be considered and complemented with consideration of spiritual and religious beliefs of adolescents. Research addressing spirituality, religiosity, and health with adolescents will be presented in order to gain an enhanced understanding of the role of spirituality and religiosity in the context of health for adolescents.

Spirituality, Religiosity, and Health in Adolescents

Spirituality and religiosity are considered protective factors for adolescents (Davis, Kerr, & Kurpius, 2003; Hodge, Cardenas, & Montoya 2001; Haglund & Fehring, 2010). Spiritual and religious variables are associated with lower anxiety (Davis et al., 2003), a greater probability of youth never using substances (Hodge et al., 2001), and greater likelihood to delay sexual activity (Haglund & Fehring, 2010). The relationship between spirituality and religiosity in managing a physical illness has not been studied extensively in adolescents. Studies conducted with adolescents reported that spiritual and religious beliefs assisted adolescents in managing illnesses such as cancer, cystic fibrosis, end-stage renal disease, and sickle cell disease (Cotton et al., 2009; Haase & Phillips, 2004; Pendleton, Cavali, Pargament, & Nasr, 2002; Snethen, Broome, Kelber, & Warady, 2004; Woodgate & Degner, 2003). While there are research studies that

examine spirituality and religiosity in specific chronic illness populations, the scope and number of studies completed is limited.

Spiritual and religious strategies used by adolescents were identified as methods for coping with chronic illnesses (Cotton et al., 2009; Haase & Phillips, 2004; Pendleton et al., 2002; Snethen et al., 2004; Woodgate & Degner, 2003). In a descriptive quantitative study using a quantitative survey, adolescents with end-stage renal disease (ESRD) who indicated having religious involvement used spirituality and religiosity as strategies for coping more often than those who did not indicate some form of religious involvement (Snethen et al., 2004). In a qualitative interpretive study, children and adolescents with cancer relied upon their religiosity for social support (Woodgate & Degner, 2003). Spiritual well-being was more frequent in adolescents diagnosed with cancer less than two years prior to the study than adolescents diagnosed more than two years prior to the study (Haase & Phillips, 2004). This finding suggests the need to understand coping differences among adolescents diagnosed with a chronic illness at birth compared to being diagnosed during various stages of development. Children and adolescents with cystic fibrosis reported using a variety of spiritual and religious coping strategies in managing their illness (Pendleton et al., 2002). In a mixed-methods study using quantitative surveys and qualitative interviews, adolescents with SCD relied upon spirituality and religiosity to help them cope with their illness (Cotton et al., 2009).

Spiritual and religious practices are protective factors used among adolescents to cope with chronic illnesses. The spiritual and religious strategies used by adolescents to cope were generally discussed. One of the gaps in understanding spiritual and religious strategies in coping is the specific manner in which strategies are used and to what level

of involvement. While there may be similar experiences among chronic illness populations, it is not realistic to apply generalizations regarding the use of spirituality and religiosity to all chronic illness populations. Gaining an understanding of differences in coping among those diagnosed with a chronic illness at birth compared to those diagnosed at different stages of development may offer additional insight in meeting spiritual and religious needs.

An overview of psychoneuroimmunology will be provided in order to enhance understanding of the mind and body relationship. The mechanism by which spirituality and religiosity can impact the mind and body relationship will also be presented. Coping, a psychosocial resource, will be discussed as a method by which spirituality and religiosity may be used in response to stress.

Psychoneuroimmunology

When discussing spirituality, religiosity, and health, the emerging research of psychoneuroimmunology is particularly important. Psychoneuroimmunology (PNI) is the study of how social and psychological factors affect the neuroendocrine and immune systems (Koenig & Cohen, 2002). The effects of psychological and physical stressors can have a negative effect on neuroendocrine and immune functioning which can be harmful and affect the body's ability to provide resistance to disease. Spirituality and religiosity are associated with decreased stress levels as well as a decrease in the negative effects stress has on the body (Dedert et al., 2004; Ironson et al., 2002; King, Mainous, & Pearson, 2002; Lynn, Paris, Frye, & Schell, 2010; Mihaljević et al., 2011; Tartaro, Luecken, & Gunn, 2005).

A general overview to include some of the key concepts of how psychological

stress affects the body is presented here. Before psychological stress can have any response on the body, the brain must first perceive an event to be a stressor (Koenig & Cohen, 2002; Rabin, 2002). Perception of the event is impacted by the person's capacity to manage stress, characteristics of the current potential stressor and additional stressors, and whether stressors are cumulative (Koenig & Cohen, 2002). If the brain recognizes an event as being stressful, the hypothalamic-pituitary-adrenal axis or the sympathetic nervous system or both will signal a physiological response to aid the body in adapting to the stressor (Black, 2003; Koenig & Cohen, 2002). Adrenal and pituitary hormones are released including catecholamines (epinephrine and norepinephrine), cortisol, adrenocorticotropic hormone, growth hormone, and prolactin (Glaser & Kiecolt-Glaser, 2005; Rabin, 2002).

Adrenocorticotropic hormone is released from the pituitary gland and acts on the adrenal gland to produce glucocorticoid hormones and catecholamines. Cortisol is a glucocorticoid which interferes with inflammatory responses and delays wound healing. Catecholamines are released from the adrenal gland and increase the amount of lymphocytes which causes an increased concentration of cytokines in the bloodstream. The increased production of cytokines also leads to poor wound healing in addition to accelerated age-related diseases (Kiecolt-Glaser et al., 2005; Lambert & Hinsley, 2011; Saunders, Kasprowicz, Kohm, & Swanson, 2001).

Most of the existing studies regarding PNI investigated the effects of stress in the adult population. Stress may cause greater susceptibility to infections, cancer, and a shortened lifespan (Herberman, 2002; Koenig & Cohen, 2002). Stress can not only increase the chances of developing an infection, but it can also lengthen the infectious

period (Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000). Stress impairs the antibody response to antibacterial and antiviral vaccines causing a weakened immune response to vaccines (Burns, Drayson, Ring, & Carroll, 2002; Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser 2000).

Depression and anxiety are likely to increase the production and circulation of pro-inflammatory cytokines which increase inflammation within the body and may lead to cardiovascular disease, osteoporosis, arthritis, type 2 diabetes, and cancer (Glaser, Robles, Sheridan, Malarkey, & Kiecolt-Glaser, 2003; Harris et al., 1999; Maes, Omelet, De Jongh, Kenis, & Bosmans, 2001). When examining the effects psychological stressors and stressful life events have on the body, inflammatory responses and pathogenic mechanisms lead to a higher incidence of chronic diseases and mortality (Harris et al., 1999; Miller, Chen, & Parker, 2011).

During a vaso-occlusive crisis, sickle-cell shaped red blood cells obstruct capillaries and restrict blood flow to an organ. The crisis leads to ischemia, pain, tissue necrosis, and organ damage. In addition, the inflammatory process is activated during a vaso-occlusive crisis, and the production and circulation of cytokines are increased (Ameringer & Smith, 2011; Conran & Costa, 2009). As mentioned previously, psychological stressors increase the amount of cytokines in the blood stream. Exposure to psychological stressors further compound the physiological state for individuals experiencing a sickle cell crisis.

Research findings suggest a connection between spirituality and religiosity with improved health outcomes and changes in physiological measures of stress and illness in adults (Dedert et al., 2004; Ironson et al., 2002; King et al., 2002; Lynn et al., 2010;

Mihaljević, et al., 2011; Tartaro, Luecken, & Gunn, 2005). Spiritual and religious beliefs and practices were associated with lower cortisol levels in adults compared to adults with fewer or no religious beliefs and practices (Dedert et al., 2004; Ironson et al., 2002; Lynn et al., 2010; Mihaljević et al., 2011; Tartaro et al., 2005). Cortisol is a biologic marker for stress and other health problems.

Lower cortisol levels were associated with spiritual or religious involvement in healthy adults and those living with chronic illnesses (Lynn et al., 2010; Ironson et al., 2002; Mihaljević et al., 2011; Tartaro et al., 2005). Women with fibromyalgia classified as having medium or high religiosity had more rhythmic cortisol profiles, and those classified as having low religiosity had flattened cortisol profiles (Dedert et al., 2004). Flattened cortisol rhythms may contribute to a number of health-related problems (Dedert et al., 2004). Greater religious involvement was associated with lower level of C reactive protein. C reactive protein is an acute inflammatory marker and is associated with cardiovascular disease (King et al., 2002).

Studies investigating child and adolescent populations are emerging. Some hesitancy exists in examining the effects of stress on neuroendocrine and immune functioning within the pediatric population. This lack of research can be attributed to the invasive nature of research, costs, and to avoid overwhelming children and adolescents with medical tests (Nassau, Tien, & Fritz, 2008). PNI correlational studies offer evidence that in response to stressors, youth with chronic diseases display negative changes in their immune system and psychological interventions can positively impact immune function (Nassau et al., 2008).

Researchers have provided information indicating that the physiological response to stress can have negative effects on the exacerbation of asthma in children and blood pressure in adolescents (Matthews, Salomon, Brady, & Allen, 2003; Sandberg et al., 2000). In a prospective quantitative study, researchers investigated if negative life events increased the risks of acute asthma symptoms in children ages 6-13 (N=90) (Sandberg et al., 2000). For children who experienced stressful events, there was a three-fold likelihood of a new asthma exacerbation over the next two weeks following the event (Sandberg et al., 2000). This response is magnified if the child lives in an environment of high chronic stress. In a study evaluating the relationship between cardiovascular reactivity to psychological stress and increases in resting blood pressure over a three year period in adolescents, blood pressure reactivity to stress did predict subsequent resting levels of blood pressure (Sandberg et al., 2000). The study did not include children with chronic health conditions. In reviewing the literature, no studies were available specifically researching the psychological effects of stress in the pediatric or adult population with sickle cell disease.

Positive spiritual thoughts and religiosity can assist in managing stress, and contribute to improved immune and physiological functioning in adults (Dedert et al., 2004; Ironson et al., 2002; King et al., 2002; Lynn et al., 2010; Mihaljević et al., 2011; Tartaro et al., 2005). Retrospective studies involving children and adolescents provide some insight on the association between stress and the negative effects on physiologic functioning (Matthews et al., 2003; Sandberg, et al., 2000).

The religious community can often provide social support across the lifespan. Spiritual and religious beliefs can lead to having a more optimal outlook on life and an

upbeat attitude resulting in improved health outcomes. Religious involvement is considered a mechanism for managing stressors and may diminish the negative effects of stress on the body (Pargament, 1997; Koenig, 2007; Young & Coopson, 2010). The impact of stress on physiologic functioning has been studied in adults, but less often in children and adolescents. Few studies have examined the association of spiritual and religious practices to psychological stressors and physiologic functioning in adults. In conducting a comprehensive review of the literature, no studies were available investigating the association of spiritual and religious practices to psychological stressors and physiologic functioning using a psychoneuroimmunology model of approach in children, adolescents, or adults with sickle cell disease.

Coping

Spirituality and religiosity are identified in the literature as mechanisms used for coping with life. The association of spirituality, religion, and coping has been understudied, particularly in the adolescent population. While the ability to cope with psychological stressors has been linked to an increased use of spiritual and religious practices, the manner in which practices are used are not consistently examined or described.

Living with a chronic illness such as SCD often poses both physical and psychological stressors. As mentioned previously in discussing psychoneuroimmunology, attending to the coping needs of individuals can impact their psychological needs, as well as alleviate some of the physiological stressors experienced during the course of disease. The connection between spirituality, religiosity, and coping has implications for one's health and are worth exploring in order to better establish the relationship between coping

and health outcomes. Health professionals working with people living with a chronic illness often take on the responsibility for assisting these individuals to identify methods and resources for coping with the stressors they experience. Assessing the coping processes and patterns of adolescents will likely offer health providers insight in determining whether the patient is experiencing spiritual distress and/or negative patterns of coping, and assist providers in identifying needed resources (Reynolds, Mrug, & Guion, 2013). This insight can be specifically applied to adolescents with SCD.

Coping comprises an encounter between the individual and a larger context of relationships and settings involving the cognitive, affective, behavioral, and physiological elements of the person (Pargament, 1997, p. 85). There is a correlation between spiritual and religious beliefs and the ability to cope. (Pargament, 1997; Koenig, 2007). This correlation is consistent in research conducted with children and adolescents (Cotton et al., 2006; Cotton et al., 2009; Cotton, Grossoehme, & McGrady, 2012; Cotton, Weekes, & McGrady, 2012; Good & Willoughby, 2006; Lyon, 2001; Snethen et al., 2004).

The spiritual and religious communities provides people with the ability to acknowledge their personal limitations and go beyond themselves for answers in order to manage their experiences (Pargament, 1997). Coping skills are considered as a factor through which religion exerts positive influences in the lives of adolescents (Smith and Lundquist-Denton, 2005). When facing a hospitalization, new diagnosis, acute illness, or chronic illness, the adolescent is at risk for physical, mental, and emotional stressors (Compas, Jaser, Dunn, & Rodriguez, 2012).

Religions offer youth a variety of cognitive and behavioral resources to address physical and psychosocial stress and difficulties. Three approaches to religious coping

include the self-directing approach, the deferring approach, and the collaborative approach (Pargament, 1997). The self-directing approach occurs when individuals do not rely on God to cope with a situation instead they rely on themselves when dealing with their thoughts and making decisions. The deferring approach takes place when people defer the responsibility of coping to God, and do not spend time thinking about how to address or resolve problems on their own. The collaborative approach occurs when the individual and God are understood as working together in order to cope. The person has a belief of a shared approach in managing difficulties.

Patterns of religious coping may be split into two categories: positive religious coping and negative religious coping (Pargament, 1997). Positive religious coping encompasses elements that provide spiritual encouragement, an optimistic redefining of negative circumstances, and mutual religious coping between the individual and God (Pargament, 1997). Spiritual encouragement may come from church congregates or church leaders in the form of offering support and negative circumstances may be redefined to give a positive perspective on a situation. Mutual religious coping embraces the concept and practice of a collaborative relationship with God. Positive religious coping is associated with positive mental and physical health outcomes as well as improvements in health.

Negative religious coping includes elements of religious pain, discontent with the congregation and/or God, and negative religious reframing (Pargament, 1997). These elements may result from feelings of abandonment or lack of support offered by a congregation. Negative religious reframing happens when negative events are evaluated using a negative perspective such as viewing undesirable events as a punishment from

God. Negative religious coping has been associated with poorer health outcomes as well as worsening health. Consideration of positive and negative patterns of religious coping provide a reference for identifying determinants of specific health outcomes.

Spiritual and religious coping is associated with positive outcomes in adolescents. Spiritual and religious coping involves the use of religion to handle stressful experiences (Pargament, 1997), and is related to better medical compliance, opinions regarding treatment, and overall comfort (Cotton et al., 2012; Grossoehme, Opipari-Arrigan, Vandyke, Thurmond, & Seid, 2011). In a quantitative study, parents (n=28) of children aged 3-12 years living with a diagnosis of cystic fibrosis were examined (Grossoehme et al., 2011). Religious coping was associated with better treatment adherence, higher self-efficacy, and a positive outlook towards treatment.

In a cross-sectional survey of adolescents aged 11-19 years, living with a diagnosis of asthma (n=151), 45% shared that their spiritual and religious beliefs helped them to cope with their asthma (Cotton et al., 2012). Ninety-two percent of the adolescents indicated that their spiritual and religious beliefs gave them some comfort.

In a cross-sectional study to include adolescents diagnosed with cystic fibrosis or diabetes (n=67, M=14.7 years), positive spiritual coping was related to fewer externalizing and internalizing problems (β = -0.21 and -.19, $p < .05$) (Reynolds et al., 2013). Negative spiritual coping was related to more externalizing problems (β = -0.20, $p < .05$) but not internalizing problems (β = 0.10, $p = .33$).

In another quantitative study adolescents aged 11-19 years with inflammatory bowel disease were surveyed and compared to their healthy peers (Cotton et al., 2009). Study results indicated that for those diagnosed with inflammatory bowel disease, the

relationship between spiritual well-being and emotional well-being had a stronger correlation in comparison to healthy adolescents. Living with a chronic illness may cause adolescents to rely on spirituality and religiosity to assist in coping with the effects of their disease.

In summary, children and adolescents living with a chronic illness use spiritual and religious beliefs and practices to manage living with a chronic disease (Cotton et al., 2012; Grossoehme et al., 2011; Reynolds et al, 2013). Spiritual and religious practices were instrumental in providing comfort (Cotton et al., 2012; Reynolds et al., 2013) and adhering to treatment recommendations (Grossoehme et al., 2011). While considered to be significant, the mechanism by which spirituality and religiosity influences coping processes and health outcomes is not clearly understood in adolescents. An aim of the current study is to explore how adolescents describe and experience spirituality and religiosity, and essentially gain insight on how their experiences may be related to living with a chronic illness.

Spirituality, Religiosity, and Sickle Cell Disease

Spirituality and religiosity may have significant implications for children and adolescents with sickle cell disease. Spirituality and religiosity have been shown to have positive correlations with health outcomes and disease (or symptom) self-management. This section will describe current literature addressing spirituality and religiosity for children and adolescents with SCD. Research addressing the spiritualty and religiosity of adolescents living with SCD was limited, thus studies of adults inclusive of older adolescents aged 18-21 with SCD were included. The current study will provide information that may aid in understanding spirituality and religiosity for adolescents with

SCD in the context of health and illness.

A literature review was completed for publication dates between January 2000 and January 2014 in order to explore research concentrating on spirituality and religiosity for adolescents with sickle cell disease. The databases searched were Cumulative Index to Nursing and Allied Health Literature (CINAHL), Health Source Nursing/Academic, ProQuest Health Module, PsycINFO, Medline, PubMed, and The American Theological Library Association (ATLA). The search strategy used in this review included the following string of terms: "Sickle Cell Disease" + "Spirit*" (for spiritual or spirituality) + "Adolescen*" (for adolescent, adolescents, or adolescence) or "x…." The alternate term included the following: children, religio* (for religion, religious, or religiosity), health, pediatric, and coping. This approach was developed to search for all published data that researched spirituality and religiosity as elements for the adolescent with SCD.

This search resulted in a list of 85 articles. The subject heading algorithm utilized by CINAHL, Medline, and PsychInfo did not completely extract search results that actually related to spirituality/religiosity and health outcomes. Due to limited studies addressing the specific topic, additional studies were reviewed if they met at least two of the following criteria: (a) discussed spirituality/religiosity in children and/or adolescents with SCD, (b) discussed spirituality/religiosity in adults when older adolescents aged 18 to 21 were included, (c) quantitative or qualitative articles published in peer-reviewed journals, and (d) discussed relevance of spirituality/religiosity to physical illness or psychosocial issues. The search method also included searching the references of reviewed studies published on spirituality and/or religiosity to include children and adolescents with SCD.

Eleven articles met the inclusion criteria and were included in this review. Eleven articles addressed spirituality/religiosity and sickle cell disease: five reported on sickle cell disease and spirituality/religiosity in the pediatric population; six reported on sickle cell disease and spirituality/religiosity in adults 18 and over (see Table 1). The literature review is organized by presenting literature addressing spirituality and religiosity in adolescents with sickle cell disease to include: adult research inclusive of older adolescents aged 18-21 years; and pediatric research inclusive of children and/or adolescents ranging in age from 5-20 years. Since few articles met the criteria, a review of each article is presented, following by a review and key findings. The key findings are organized into one main category and four threads. The main category is spirituality and religiosity as sources for coping strategies. The threads include: (a) spiritual and religious coping strategies and pain management, (b) spiritual and religious coping strategies and health care utilization, (c) spiritual and religious coping strategies and quality of life, and (d) positive and negative religious coping. Following the review is a summary of gaps in the literature.

Table 1.

Selected Characteristics of Studies of Spirituality and Religiosity of Persons with SCD

Study	Sample	Design	Primary Results
Adegbola, 2011	N=90 ages $\geq$18; 23 males and 67 females	Descriptive correlational	Spirituality and quality of life (QOL) significantly correlated; spirituality and self-efficacy predicted QOL; spirituality and self-efficacy accounted for more than half of the variance on QOL reports
Anie et al., 2002	N=67 ages 7 to 15; 37 males and 30 females	Cross-sectional	Praying and hoping most commonly used active coping measures; active coping directly correlated with increased use of healthcare resources; active coping not related to pain
Bediako et al., 2011	N=93 ages $\geq$18; males & females	Cross-sectional	Positive religious coping significantly related to less hospital admissions
Cooper-Effa et al., 2001	N=71 adults; mean age 35 years;	Cross-sectional	Spiritual well-being was correlated with perception of life control;

41 males and

59 females

spirituality significantly related to

QOL; existential well-being is

Study	Sample	Design	Primary Results
			associated with managing pain
Cotton et al., 2012	N=19 ages 5-10; 9 males and 11 females	Qualitative	Children described God as a functional God (provided practical care), emotional God (provided comfort when in pain), or both; prayer was common coping strategy for stressful experiences
Cotton et al., 2009	N=48 ages 11-19; 23 males and 25 females; N=42 parents mean age 32 years; 2 males and 40 females	Mixed method	Adolescent participants and parents demonstrated high levels of faith and religious practices
Harrison et al., 2005	N=50 ages 18 to 70; 22 males and 18 females	Cross-sectional	Increased religious involvement (church attendance) significantly related to less pain
Mann-Jiles & Lynn Morris, 2009	N=62 ages ≥ 18 25 males and 37 females	Cross-sectional	Increased spirituality significantly related to increased QOL
O'Connell	N=67 ages 18 to 70	Cross-	Moderate prayer significantly related

Study	Sample	Design	Primary Results

et al., 2009   30 males and   sectional   to less anxiety; low to moderate

church attendance related to shorter

hospital stays, emergency

department visits, and

hospitalizations

Study	Sample	Design	Primary Results
Sibinga et al., 2006	*N*=57 children mean age 8 years; 29 males and 28 females; *N*=57 parents/guardians ages 15 to 65; males and females	Cross- sectional telephone survey	42% of parents used bioenergetic methods including prayer and spiritual healing. Parents more likely to use prayer and spiritual healing with their children who were older, had severe SCD symptoms, a higher perceived impact of SCD on the child's life
Yoon & by Black, 2006	*N*= 63 ages 1 to 20; *N*=63 parents/guardians ages 16 to 74; males and females	Cross- sectional	Increased use of pain medications children was related to increased use of therapies such as prayer, spiritual healing, massage, and relaxation

Adolescent/Pediatric Research

This section of the review is inclusive of children and/or adolescents aged 5-20 years

living with SCD. In five studies, spiritual and religious practices were identified in the routines of children and adolescents with SCD and their caregivers. Examples of spiritual and religious practices included prayer, spiritual healing by others, asking for love and forgiveness, and seeking God's love and care (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga, et al., 2006; Yoon & Black, 2006). Spirituality and religiosity were identified as assisting in managing a chronic illness, impacting quality of life, and impacting health care utilization for children and adolescents with SCD.

Incorporation of spiritual and religious practices were evident in adolescents and caregivers of children with SCD (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2006; Yoon & Black, 2006). Spiritual and religious practices were used to improve the physical or mental state of the individual. Spiritual and religious strategies have been used as alternative strategies to enhance the clinical care of patients. Bioenergetic therapies to include prayer and spiritual healing are examples of spiritual and religious strategies.

Prayer and spiritual healing were identified as strategies used most often in parents or guardians of children with SCD, and by children and adolescents themselves (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2006; Yoon & Black, 2006). A cross-sectional survey study assessed the frequency of the reliance on alternative therapies by parents. Prayer and spiritual healing were used frequently. Of parents in this study 54% used some type of alternative therapy including 42% who utilized bioenergetic methods. Prayer and spiritual healing were categorized as bioenergetic methods (Sibinga et al., 2006). This cross-sectional quantitative study included 57 parents of children with SCD. The mean age of children in this study was 8.2

years (*SD*= 5.3). Parents were more likely to use prayer and spiritual healing with their

children who were older (mean ages of 9.7 years versus 6.4 years), had higher scores on

SCD severity scale (OR 1.33, 95% CI 1.02, 1.72; *p* = 0.03), had a higher perceived

impact of SCD on the child's life ("tremendous" versus "no" impact, *p* = 0.02), and

multiple hospitalizations within the preceding 12 months (p = 0.05) (complete results of

statistical test for this study were not provided). Parents who used prayer and spiritual

healing for themselves and those who had a higher level of education were more likely to

use prayer and spiritual healing with their SCD affected children (Sibinga et al., 2006).

Among all parents who used any type of alternative therapy, 83% felt that this could be

helpful although how it might be helpful was not described (Sibinga et al., 2006). Most

respondents expressed an interest in discussing alternative therapies with their providers

(70% with pediatrician; 76% with hematologist) but only one-third of respondents felt

their providers were interested (Sibinga et al., 2006). Spiritual and religious practices

were significant for caregivers of children living with SCD. Many used this form of

alternative practices with their children and the majority of caregivers were interested in

discussing this option with their health providers.

A second study investigated the frequency of caregiver use of alternative

strategies for pain management for their SCD affected children. In this quantitative,

cross-sectional descriptive study, more than 70% of caregivers (*n* = 44) used some form

of therapy such as prayer, spiritual healing by others, massage therapy, relaxation,

administering megavitamins, or administering herbal products. Of these modalities, more

than 70% of the caregivers used self-prayer and more than 50% utilized spiritual healing

(Yoon & Black, 2006). Self-prayer and spiritual healing were used more frequently with

children who used two or more analgesics (Yoon & Black, 2006). The mean age of their

children was 9 years (*SD* = 6.4). This study included 62 adult caregivers of children with

SCD. Generalization of the use of therapies among caregivers is limited as convenience

samples were used (Sibinga et al., 2006; Yoon & Black, 2006). Surveys from the child or

adolescent with SCD were not always obtained, and impact results of research. Use of

alternative therapies was significant and caregivers considered the topic to be important

to discuss. Participants indicated that children using two or more pain medications were

more likely to use spiritual or religious alternative therapies (Yoon & Black, 2006), but

there was no indication on the use of pain assessments by caregivers and the timing of

alternative therapies. Both studies incorporate spiritual and religious strategies as a type

of alternative therapy used by caregivers of patients with SCD. Exploring spirituality and

religiosity as a strategy used by caregivers of children with SCD was not the specific aim

for either study. The scope in understanding the relevance of spiritual and religious

strategies is limited.

In three studies researchers examined the use of spiritual and religious beliefs to

manage and cope with SCD (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012).

Adolescents living with SCD used religion to cope with their experiences and make

requests for their parents to engage in spiritual practices on their behalf. Using a mixed

methods approach (quantitative surveys and qualitative interviews), researchers in one

study surveyed 48 adolescents with SCD and 42 parents about how they used spirituality

and religiosity to cope with their illness (Cotton et al., 2009). In this study, a 216-item

survey was administered to adolescents. Adolescents were asked to rate how spiritual and

religious they were using a 4 point Likert scale ranging from "not at all" to "very." The

importance of religion and belief in God was also assessed using a 4-point Likert scale ranging from "strongly agree" to "strongly disagree." The Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp) Scale was used to examine spirituality. The FACIT-Sp is a 12-item measure asking adolescents to respond indicating how true statements are about them using a Likert scale ranging from "0" ("not at all") to "4" ("a great deal"). A total score is summed based on responses ranging from 0 (indicating the lowest level of spirituality) to 48 (indicating the highest level of spirituality).

The Brief RCOPE was used to assess positive and negative religious coping. The Brief RCOPE is a 14-item instrument with responses indicating the frequency with which adolescents have used religious coping behaviors on a Likert scale of "1" ("not at all") to "4" ("a great deal"). Health-related quality of life (HRQOL) was the outcome variable. The PedsQL was used to assess the outcome variable and is a 15-item scale used to assess physical, emotional, social, and school functioning. Scores range from 0 to 100 with higher scores representing better HRQOL. A 20-30 minute qualitative interview was conducted with adolescents and included 18 questions developed by the investigators to assess the role religious coping played for adolescents with SCD. Nonmatched parents of adolescents with SCD were given a 73-item survey to include items and measures assessing spirituality (FACIT-Sp), religiosity, and religious coping (Brief RCOPE). The outcome variable was the parent-reported HRQOL with scores ranging from 0 to 100 with higher scores representing better HRQOL.

Of the 37 adolescents completing quantitative surveys, 35% (*n*=13) prayed once or more daily for symptom management, 64% (*n*=24) prayed a minimum of once per week, and 51% (*n*=19) reported attending religious services a minimum of once per week

(Cotton et al., 2009). The overall mean for FACIT-Sp scores was relatively high (M = 35.9, SD = 7.9) as well as FACIT-Sp meaning/peace (M = 24.4, SD = 5.9) and faith (M = 11.5, SD = 3.4). Approximately 73% of adolescents (n=27) asked for forgiveness of sins, 67% (n=25) looked for a stronger connection with God/ a Higher Power, and 64% (n=24) sought God's love and care.

Positive and negative religious coping strategies were identified using the Brief RCOPE. Positive strategies listed included: (1) the adolescent looking for a stronger connection to God, (2) seeking God's/a Higher Power's love and care, (3) seeking help from God/a Higher Power in letting go of their anger (4) trying to put their plans into action with God/a Higher Power, (5) trying to see how God/a Higher power might be attempting to strengthen them in the situation, (6) asking forgiveness of sins, and (7) focusing on religion to stop worrying about problems (Cotton et al., 2009). Negative strategies included: (1) wondering whether they were abandoned by God/a Higher Power, (2) because of lack of devotion feeling punished by God/a Higher Power, (3) wondering what they did for God/ Higher Power to punish them, (4) questioning God's/ a Higher Power's love for them, (5) wondering if their church had abandoned them, (6) deciding the devil made this happen, and (7) questioning the power of God/a Higher Power.

Adolescents reported greater use of positive religious coping strategies than negative religious coping strategies (22% to 47% reported using each strategy "a great deal"). Parents also reported greater use of positive religious coping strategies than negative religious coping (29% to 62% reported using each strategy "a great deal"). Adolescents reported greater negative religious coping than nonmatched parents, t (76) = -2.01, $p < 0.05$. Eleven adolescents completed the qualitative interviews and 100%

reported a belief in God. Adolescents described religion as guiding them when making decisions about whether or not to engage in risky behaviors. Adolescents indicated that having their parents pray was relevant. School functioning was positively associated with overall spirituality ($r = 0.57$, $p < .01$) (Cotton et al., 2009). This was the only study in which a mixed method design was used for adolescents with SCD, and responses were obtained from both the parent and the adolescent. In addition, this was the only study noted to examine spiritual and religious coping exclusively in adolescents with SCD.

In a second study, praying and hoping were used as a combined coping strategy by children and adolescents with SCD. Children and adolescents (N=67) aged 7 to 15 years were included in a quantitative study to determine if spirituality and religiosity were helpful methods of coping with pain. The Coping Strategies Questionnaire for SCD (CSQ-SCD) was used to determine strategies for coping with pain. Children rated their responses using a Likert scale with "0" being "never" to "6" being "always." Participants used praying and hoping as an active coping strategy having the highest mean of 3.49 in comparison to all of the active coping strategies identified and utilized (Anie et al., 2002). Use of active coping was identified as having a direct correlation with more utilization of hospital services for children and adolescents (- $\beta = 0.34$, F change = 3.13, $p = .4$), but this was not related to pain (Anie et al., 2002). Prayer and hoping were combined as one active coping strategy, and the average score for prayer alone cannot be determined.

In the last study, prayer was identified as a religious strategy used to cope with SCD. The majority of the children (12) relied upon their religion to cope with SCD. Religious coping strategies included relying upon religion to manage and provide comfort when they were sick or in pain and give meaning during stressful events related

to SCD (Cotton et al., 2012). A qualitative approach used semi-structured interviews and an art drawing exercise to elicit information from 19 children aged 5 to 10 years (average age 8.05 years ± 1.81) with SCD. Children described God as a functional God (provided practical care), emotional God (provided comfort when in pain), or both. A couple of the children reported being disappointed by God's response or lack of response to their illness. Prayer was a common coping strategy and religious methods for coping gave meaning when facing stressful experiences. This study used a mixed method approach providing quantitative and qualitative results.

In summary, drawing upon spiritual and religious practices was common for children and adolescents diagnosed with SCD and their parents/guardians to manage symptoms and cope with SCD (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2006; Yoon & Black, 2006). The relationship of spiritual and religious practices to health outcomes and service utilization was discussed (Anie et al., 2002). Two of the studies reviewed were based on the perspectives of parents (Sibinga et al., 2006; Yoon & Black, 2006). Limitations of the available research include inconsistent definitions, lack of connection of use of spiritual and religious practices to outcomes, lack of data from children and adolescents themselves, and limited generalizability.

In two studies, prayer and spiritual healing were explored but not defined (Sibinga et al., 2006; Yoon & Black, 2006). Praying and hoping were combined as an active coping strategy with no definition of terms whether as separate concepts or as a combined concept (Anie et al., 2002). Lack of definitions and combining concepts may impede understanding of how each is relevant to coping with SCD.

A description of how current spiritual and religious practices helped was not identified. The desire of parents and guardians to discuss spiritual and religious practices as part of alternative strategies with their health providers was not addressed. Documentation of pain experiences to include a complete pain assessment with consideration of spiritual and religious strategies may provide valuable information. Examining how spiritual and religious practices affect outcomes such as pain severity and SCD pain crisis was not specifically investigated.

Use of spiritual and religious practices is common among younger children (Anie et al., 2002; Sibinga et al., 2006; Yoon & Black, 2006). Only one study examined spiritual and religious practices specifically among adolescents (Cotton et al., 2009). Two studies sought the parents' perspectives alone as opposed to the child/adolescent and parent perspectives (Sibinga et al., 2006; Yoon & Black, 2006). Understanding why adolescents report higher levels of negative religious coping than their parents/guardians will likely assist caregivers and health providers in supporting adolescents. Research addressing the adolescent population living with SCD specifically and obtaining their perspectives is warranted. Finally, the studies reviewed used convenience sampling which limits generalizability.

Older Adolescent/Adult Research

This section of the review examines adult studies inclusive of older adolescents aged 18-21 years. Much of the research on the association of spirituality, religiosity, and health has been conducted with adults. This population of adults includes those living with SCD. Since studies addressing the spiritual and religious needs of adolescents with SCD are limited, studies encompassing adults with SCD are reviewed. Information from

the studies may provide insight regarding living with a chronic illness such as sickle cell disease from a developmental lens. Examining the experiences of adults and how they frame their experiences may provide knowledge on how to assist adolescents across the lifespan.

Adolescents and families with SCD are generally part of a larger community. Family has a significant role in the spiritual development of their children (Roehlkepartain et al., 2011; Smith and Lundquist-Denton, 2005). Of youth (*N*=7,200) surveyed in eight countries, 44% indicated that family has influence on their spiritual lives (Roehlkepartain, 2008). Observation of family and community dynamics may offer an enlightened understanding of individual relationships and the influence of adult spiritual and religious practices on adolescents.

This section of the review will identify current literature addressing spirituality and religiosity for adults with SCD to include adolescents aged 18 and older. In three studies, spiritual and religious practices were identified in the routines and self-management practices of adults with SCD (Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009). Examples of spiritual and religious practices identified include prayer, church attendance, meditation, and Bible study. Spirituality and religiosity had an impact on managing symptoms of the disease, coping with the disease, pain experiences, quality of life, and hospital admissions in adults with SCD (Bediako et al., 2011; Cooper-Effa et al., 2001; Harrison et al., 2005; Mann-Jiles & Lynn-Morris, 2009; O'Connell-Edwards et al., 2009).

Three studies examined the association of spiritual and religious coping with pain experiences (Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al.,

2009). Using strategies for religious coping resulted in decreased reports of anxiety and hostility, but pain scores were not significantly affected by frequency of prayer (O'Connell-Edwards et al., 2009). Spiritual well-being or use of religious coping strategies was associated with decreased reports of pain (Harrison et al., 2005). Pain scores were higher in participants who attended church more frequently (O'Connell-Edwards et al., 2009).

In a recent quantitative study, religious coping was explored in a cross-sectional survey study of 67 patients with a mean age of 36.8 years (*SD* = 11.5) (age range 18-70 years) (O'Connell-Edwards et al., 2009). The study represented first-year data collected as part of a five-year, longitudinal evaluation of medical and psychological influences on pain and pain-related morbidities in patients with SCD. The Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease (LEMPFSCD) is a 700-item multidimensional self-report measure designed for patients with SCD. The LEMPFSCD is comprised of eight content-driven instruments for the assessment of psychiatric, behavioral, and social functioning. For this, study the following content areas were examined: demographics, pain, psychopathology, and religious coping. Pain severity was measured with the Short Form McGill Pain Questionnaire (SF-MPQ) which is structured to qualitatively and quantitatively assess pain. A visual analog scale (VAS) consisting of a 100-mm line ranging from "no pain" at one end and "worst imaginable pain" at the opposite end was used to rate pain. The Symptom Checklist 90-Revised (SCL-90-R) was used to evaluate the magnitude of common psychopathologies. Responses range from "0" ("not at all") to "4" ("extremely").

Frequency of church attendance or prayer was categorized as low, moderate, or

high. Engaging in church attendance or prayer once or more per day was categorized as "high", most or some days was categorized as "moderate," and "once in a while" or "never" was categorized as "low." Post-hoc *t* tests revealed that participants who endorsed moderate occurrence of prayer, praying "most" or "some" days reported significantly less anxiety ($M = 47.18$, $SD = 3$, $p = .004$) and hostility ($M = 44.24$, SD = 2.66, $p = .02$) (O'Connell-Edwards et al., 2009). Results also demonstrated low to moderate frequency church attendance was associated with better clinical outcomes (O'Connell-Edwards et al., 2009). There were fewer hospitalizations ($M = 4.82/7.21$, SD = 1.98/2.40), fewer days in the hospital ($M = 0.82/1.58$, $SD = 0.38/0.47$), and fewer emergency department visits ($M = 3.03/2.89$, $SD = 1.33/1.61$) (O'Connell-Edwards et al., 2009). Analysis of data suggests that moderate frequency of prayer has better outcomes in comparison to low or high extremes of prayer. The study explored general religious coping but did not examine measures of positive and negative religious coping. The study included adults of various ages. Findings suggest that patients who exercise a moderate approach to coping are engaged in healthy coping behaviors and religious activities in comparison to patients who engage in an extreme approach to coping (O'Connell-Edwards et al., 2009).

In a second study the significance of spirituality and religiosity on the experience of pain in adult patients with SCD was examined (Harrison et al., 2005). The Longitudinal Exploration of Medical and Psychosocial Factors in Sickle Cell Disease (LEMPFSCD) was administered to each participant. The following measures were examined: pain, religiosity, psychological distress, and social desirability. Pain severity was measured with the SF-MPQ and a VAS. Religious involvement was assessed with

the Duke Religious Index. The Duke Religious Index is a five-item scale that captures

three major components of religiousness: public organizational, private non-

organizational, and intrinsic religiosity (Koenig, Meador, & Parkerson, 1997). Public

organizational religiosity is measured by religious attendance; private-nonorganizational

religiosity is measured with questions about prayer and Bible study; and intrinsic

religiosity is measured by subjective reports of spirituality and religiosity as expressed by

religious beliefs and experiences. The participants in this study consisted of adults with

the youngest participant being 18 years of age and the oldest 70 ($M = 36.8 \pm 12.1$).

Religious involvement as measured by church attendance was related to significantly

fewer affective and sensory dimensions of pain (sensory, $t = -3.42$, $p = .0013$; affective

subscale, ($t = -4.42$, $p < .0001$) in African American patients with SCD (Harrison et al.,

2005). Participants also experienced lower overall pain intensity as indicated by the VAS

($t = -4.00$, $p < .001$) and present pain index ($t = -3.57$, $p = .017$). They had lower levels

of somatization ($t = -2.54$, $p = 0.14$), interpersonal sensitivity $t = -2.50$, $p = .016$),

depression ($t = -2.35$, $p = .023$), and anxiety ($t = -2.92$, $p = .005$) using the SCL-90-R.

Frequency of private non-organizational religiosity did not correlate with measures of

pain or mental health. Intrinsic religiosity was categorized into two categories. The first

category consisted of those scoring "high" on the intrinsic religiosity measure (having the

maximum score of 15 on the intrinsic religiosity measure). This group was compared to

"all others" in the group (having a score of less than 15 on the intrinsic religiosity

measure). There was no significant difference in reports of pain based on intrinsic

religiosity.

In a third study, the role of spirituality in patients with SCD was examined. A

quantitative descriptive cross-sectional study (n=71) examined the relationship between spiritual well-being and coping with pain for adults with sickle cell disease (Cooper-Effa, et al., 2001). The Spiritual Well-Being Scale consists of 20 items using a Likert scale and was used to measure spiritual well-being (SWB). The SWB scale is divided into two subscales with 10 items focusing on life satisfaction and life direction, and referring to existential well-being (EWB) and 10 items focusing on belief in God and referring to religious well-being (RWB). Ability to cope with pain was assessed using the West Haven-Yale Multidimensional Pain Inventory, which consisted of three parts. The first part assessed the patient's appraisal of pain; the second part assessed the impact of pain on an individual's life; the third part assessed the extent to which patients were able to participate in activities of daily living. The population was found to demonstrate high levels of spirituality and religiosity. SWB did not correlate with the level of interference with daily activities (p =.19 for EWB; p = .91 for RWB) or pain severity (p = .24 for EWB; p = .29 for RWB). While perceived pain severity did not correlate with SWB, SWB is considered to be significant for people who must deal with the pain of the disease. In this study, SWB correlated with a better perception of life control for patients with SCD (p= .00 for EWB; p= .01 for RWB). Results suggest that SWB is associated with enhanced life satisfaction and enhanced life direction (Cooper-Effa et al., 2001).

Data from a large prospective study were extracted to examine the relationship between religious coping and hospital admissions among adults with SCD (n = 95). Using hierarchical regression analysis, positive religious coping was found to be related to significantly fewer admissions in adults with SCD over a 12-month period (M = 1.29, β = -0.29, p = .05) when compared to adults who endorsed lower levels of religious

coping (M = 4.23). Religious coping was assessed using three positive and two negative items from the brief RCOPE. Multiple regression analysis demonstrated that among six potential predictors (diagnosis and severity, age, gender, education, positive and negative religious coping), only one factor predicted hospital admissions: positive religious coping. Positive religious coping was related to significantly fewer hospital admissions (β = -0.29, p < 0.05) independent of other predictors (Bediako et al., 2011). Pain assessments were not included with data collection.

A quantitative descriptive study examined the quality of life in adult patients with SCD aged 18 and older. When patients were asked if they considered themselves spiritual, 58% of the participants (n = 36) described themselves as being very spiritual (Mann-Jiles & Lynn-Morris, 2009). The average Quality of Life Scale for healthy populations was 90, whereas for patients with sickle cell disease the mean was 83.6 (Mann-Jiles & Lynn-Morris, 2009). A total of 58% of the study participants described themselves as spiritual with study results being significant for an individual's perception of spirituality, t (59) = -2.970, p < .05 (Mann-Jiles & Lynn-Morris, 2009). Study participants were more likely to focus on what gives meaning to their lives rather than religious routine and practices specifically when considering quality of life issues.

In summary, spirituality and religiosity were associated with managing the pain experiences of adults living with SCD (Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009). Most adults exhibited moderate to high levels of spirituality and religiosity (Bediako, 2011; Cooper-Effa et al., 2001; Harrison et al., 2005; Mann-Jiles & Lynn-Morris, 2001; O'Connell-Edwards, 2009). Spiritual and religious practices to include church attendance and moderate frequency of prayer were associated

with lower levels of anxiety and hostility (O'Connell-Edwards et al., 2009).

Spirituality has an impact on the lives of adult SCD patients (Cooper et al., 2001; Mann-Jiles & Lynn-Morris, 2001) and correlated with a perception of greater life control (Cooper et al., 2001). The process through which spirituality increases one's perception of life control was not apparent. Perception of individual spirituality was a significant demographic variable for quality of life scores (Mann-Jiles & Lynn-Morris, 2009). Variables such as SCD type, gender, marital status, employment status, income level, living situation, age, religious involvement, and education were not statistically significant variables.

Use of positive religious coping by adults living with SCD has an impact on healthcare utilization (Bediako et al., 2011). Spiritual and religious concepts and practices were not defined and described with each study. While pain is a frequent and major symptom experienced by the SCD population, a pain assessment was not always included as part of the data collection.

In reviewing the 11 studies, one main category and four subcategories emerged. The main category was spirituality and religiosity as sources for coping strategies. The four subcategories include: (a) spiritual and religious coping strategies and pain management, (b) spiritual and religious coping strategies and health care utilization, (c) spiritual and religious coping strategies and quality of life, and (d) positive and negative religious coping strategies. The category and subcategory topics are used to organize findings from the literature review.

Spirituality and Religiosity as Sources for Coping Strategies

A comprehensive review of the literature revealed that there is no study, to this author's knowledge, using qualitative methods exclusively to explore spirituality and religiosity in adolescents with SCD. This represents a major gap in the literature. Reviewed literature examines spirituality and religiosity as mechanisms for coping rather than exploring these elements of the human person as antecedents for coping.

In five studies spiritual and religious practices were identified in the routines of adolescents and children with SCD or their caregivers. Examples of spiritual and religious practices include prayer, spiritual healing by others, asking for love and forgiveness, and seeking God's love and care (Anie et al., 2002; Cotton et al., 2012; Cotton et al., 2009; Sibinga, et al., 2006; Yoon & Black, 2006). Spirituality and religiosity were identified as support in managing a chronic illness, improving quality of life, and impacting health care utilization for adolescents living with SCD.

Incorporation of alternative strategies to include spiritual and religious practices were evident in adolescents and children with SCD (Sibinga, et al., 2006; Yoon & Black, 2006). Spiritual and religious practices may be used by caregivers of the children or by the children themselves to cope. Two research articles discussed spiritual and religious practices used by parents of children and adolescents with SCD as an approach to coping and enhancing clinical care (Sibinga et al., 2006; Yoon & Black, 2006). Prayer and spiritual healing were identified as spiritual and religious strategies used most often by parents or guardians of children with SCD (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2006; Yoon & Black, 2006). Spiritual and religious practices were significant for caregivers who used them with their children with SCD (Sibinga et

al., 2006; Yoon & Black, 2006). Researchers assessed the frequency of the reliance on alternative therapies by parents.

Parents who used spiritual and religious practices with their children or adolescents with SCD were interested in discussing alternative therapies with their children's providers, or felt spiritual and religious coping strategies would be helpful (Sibinga et al., 2006; Yoon & Black, 2006). While parents desired to review alternative therapies with providers, some felt providers were not interested (Sibinga et al., 2006). Only one-third of respondents felt their providers were interested in discussing spiritual and religious strategies (Yoon & Black, 2006). Findings from both of the aforementioned studies were printed in 2006. Since 2006, to the researcher's knowledge, no studies have been identified that are inclusive of the SCD population and address parental interests in spiritual and religious strategies for coping. In addition, no studies to this researcher's knowledge, have addressed why most parents would think that their children's providers were not interested in discussing the use of spiritual and religious strategies.

Parents were more likely to use prayer and spiritual healing with their children who were older, had higher scores on the SCD severity scale, had a higher perceived impact of SCD on the child's life, higher education of parent respondent, taking a greater number of pain medications, and multiple hospitalizations within the preceding 12 months (Sibinga et al., 2006; Yoon et al., 2006). While researchers for two studies identified significant instances when parents were more likely to use spiritual and religious strategies, there remains a gap in providing overall descriptions of how strategies are used. Specifically why strategies were used more often with older children, and whether parents used strategies primarily based upon their perception of their child's

health status, or on behalf of requests made by the child. Parents who used prayer and spiritual healing for themselves and those who had a higher level of education were more likely to use prayer and spiritual healing with their SCD affected children (Sibinga, et al., 2006). In the second study, respondent education level was obtained, but no comparisons were made between education level, and use of spiritual and religious strategies (Yoon & Black, 2006). Responses were not obtained from the children (Sibinga et al., 2006; Yoon and Black, 2006). Parents' perceptions were not obtained in the current study, but adolescents are given a voice in describing their experiences.

Adolescents and children with SCD used prayer and hoping as spiritual and religious coping strategies (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012). Prayer and spiritual healing were identified as spiritual and religious strategies used most often by adolescents (Anie, et al., 2002; Cotton et al., 2009). In a study of children with SCD, prayer was identified as a religious coping strategy used to cope with the symptoms of SCD in more than half of the population (Cotton et al., 2012). More than half of the children relied upon their religion to cope with SCD. Spiritual and religious coping strategies included relying upon religion to manage and provide comfort when they were sick or in pain and give meaning during stressful events related to SCD (Cotton et al, 2012). For one study the most common spiritual and religious coping strategies included asking forgiveness for sins and seeking God's love (Cotton et al., 2009). It is possible that these strategies were incorporated into the adolescents' prayers and categorized as such, but this was not specified. In one study, participants used praying and hoping more than all of the active coping strategies identified and utilized such as calming self-statements, diverting attention, and reinterpreting pain sensations (Anie et al., 2002).

Spirituality and religiosity were used as a source of coping in adults inclusive of older adolescents aged 18-21 years (Bediako, 2011; Cooper et al., 2001; Harrison et al., 2005; O'Connell et al., 2009). Praying, Bible study, and church attendance were religious methods used for coping with SCD. Positive and negative religious coping were evaluated in one study (Bediako, 2011).

Adult studies focused on examining the association of spirituality and religiosity with specific outcomes rather than the manner in which spiritual and religious strategies were used (Harrison et al., 2005; O'Connell-Edwards et al., 2009). Types of spiritual and religious strategies used by adults were mentioned, but only generally described.

One adult study made reference to consideration of holistic care to include the biophysical, psychological, sociocultural, and spiritual elements of the person (Adegbola, 2011). Studies investigating the relationship between spirituality and religiosity with stress and physiologic functioning in adolescents are warranted. Adolescence can be a stressful stage of development and when coupled with a severe chronic illness the effects of stress can be complex. Identifying potential sources of support, to include religion and spirituality, may offer guidance in establishing optimal health and well-being for adolescents with SCD. Resources that are identified as being helpful for adolescents may be a source of ongoing support during their adult years and merit exploring.

A definition of spirituality or religiosity was provided in one pediatric study (Cotton et al., 2009) and in three studies inclusive of adults (Adegbola, 2011; Cooper-Effa et al., 2001; Mann-Jiles & Lynn-Morris, 2009). In a pediatric study religious coping was described (Cotton et al., 2012). Two studies discussed the relevance of spirituality or religiosity, but a definition was not presented (Bediako et al., 2011; Harrison et al., 2005).

Consistent inclusion of defined concepts will aid in understanding the relationship between concepts and the impact on coping.

Spiritual and Religious Coping Strategies, and Pain Management.

In six studies, results indicated that spiritual and religious coping strategies were used to manage pain. Three studies addressed spiritual and religious coping strategies and pain management in adults (Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009), three studies addressed spiritual and religious coping strategies and pain management in adolescents and children (Anie et al., 2002; Sibinga et al., 2006; Yoon & Black, 2006).

Pain was identified as being a significant variable when considering the association of spiritual and religious coping strategies (Anie et al., 2002; Cooper-Effa, et al., 2001; Cotton et al., 2009; Cotton et al., 2012; Harrison et al., 2005; O'Connell-Edwards et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). The association of spirituality with pain experiences was explored. Spiritual and religious coping strategies were associated with decreased reports of pain (Cooper-Effa et al., 2001; Harrison et al., 2005). Increased use of pain medication and SCD severity was associated with greater use of spiritual and religious strategies (Sibinga et al., 2006; Yoon and Black, 2006). A SCD severity scale included a health rating, measures of SCD pain, hospitalizations, disease and impact (Yoon and Black, 2006). For one study the use of pain reports was not selected, but rather hospital admissions as an objective indicator. This process was chosen to avoid the limitations encountered with use of subjective data (Bediako, 2011). While not assessed, the presence of pain was included in the overall score for a type of quality of life (QOL) survey (Adegbola, 2011; Cotton et al., 2009; Mann-Jiles & Lynn-

Morris, 2009). There was a positive correlation between spirituality and QOL.

Spiritual and religious practices to include church attendance and moderate frequency of prayer were associated with the lowest scores for pain severity in adults (Harrison et al., 2005; O'Connell-Edwards et al., 2009). Caregivers used spiritual and religious coping strategies more often in caring for their SCD affected children who were ≥ 13 years (Yoon & Black, 2006). The authors provide possible explanations of parents being concerned about their adolescent's pain severity and employing more than one intervention, or concern over opioid use.

A study specifically examined hospital admissions in relation to religious coping rather than subjective responses such as pain severity (Bediako, 2011). This objective to build upon previous inquiry in researching the relationship between spirituality, religiosity, and SCD is valuable. Pain crises are frequently experienced by those with SCD and a multidimensional phenomenon affecting their QOL. Understanding the experiences of adolescents with SCD warrants a multidimensional approach to explore the use of spiritual and religious coping strategies.

Spiritual and Religious Coping Strategies, and Health Care Utilization

Adolescents and children who responded to pain using active coping strategies (to include spiritual and religious strategies) were more likely to be hospitalized (Anie et al., 2002). The authors indicate that seeking care from a hospital may be an example of their active coping strategies. The authors also concluded that hospital utilization was not predicted by their pain experiences.

Participants who indicated having more experiences of positive religious coping, demonstrated fewer hospitalizations over a 12-month period (Bediako, 2011). While

sickle cell disease type was identified as a study variable, disease type is not a consistent indicator of pain severity. This may impact interpretation of the relationship between religious coping and hospital admissions. The authors do present a good argument that using religious activities as a study variable can be confusing in understanding the relationship of spirituality and religiosity to health outcomes. Two studies included demographic data of the number of hospitalizations or medical visits for participants in the last year prior to the study (Cooper-Effa et al., 2001; Sibinga et al., 2006). This variable was used to determine disease severity and no associations were made with spiritual and religious coping and health care utilization.

Frequency of church attendance was directly associated with health care utilization including number of hospitalizations and number of days in the hospital (O'Connell-Edwards et al., 2009). Low to moderate frequency church attendance was associated with better clinical outcomes and less health care utilization (O'Connell-Edwards et al., 2009). Evaluation of study results also indicated that the higher the frequency of church attendance, the higher the frequency of health care utilization. Analysis of data suggests that moderate frequency of prayer has better outcomes in comparison to low or high extremes of prayer. This finding suggests that the complexity of illness may cause individuals to rely more on their spiritual and religious coping strategies. It may also indicate that the more individuals rely on spiritual and religious coping strategies, the more likely they are to seek out health resources in general. Moderate frequency of prayer was associated with the highest frequency for number of hospitalizations, number of days hospitalized, and emergency department visits. The authors suggest that there may be specific characteristics, such as healthy coping

behaviors, of those engaged in moderate spiritual and religious coping strategies that cause them to utilize health care resources more often. This concept should be further explored.

Spiritual and Religious Coping Strategies, and Quality of Life

In an adult study spirituality was associated with enhanced life satisfaction and enhanced life direction (Cooper-Effa et al., 2001). The mechanism of this association is not clearly understood. In another previously mentioned study, Health Related Quality of Life (HRQOL) in adolescents with SCD was evaluated (Cotton et al., 2009). School performance was evaluated in relation to overall spirituality. Higher spirituality was associated with better school performance. Two quantitative descriptive studies examined the quality of life (QOL) in patients with SCD aged 18 and older (Adegbola, 2011; Mann-Jiles & Lynn Morris, 2009). The mean Quality of Life Scale scores (QOLS) for healthy populations was 90, whereas for patients with sickle cell disease the mean QOLS score was 83.6 (Mann-Jiles & Lynn Morris, 2009). QOL was directly related to the individual's perception of spirituality, t (59) = -2.970, $p < .05$ (Mann-Jiles & Lynn Morris, 2009). Those with higher levels of spirituality also had higher QOL scores. Study participants were more likely to focus on what gives meaning to their lives rather than religious routine and practices specifically when considering QOL issues. In a second study in which quality of life was examined, the relationship between QOL, spirituality, and self-efficacy was examined (Adegbola, 2011). There was a significant relationship between the perception of QOL and spirituality, r (88) = 0.68, $p < .05$.

Positive and Negative Religious Coping

One study examined religious coping in both adolescents and parents (Cotton et al., 2009). Adolescents used more negative coping strategies than their nonmatched parents. This observed difference between adolescents and their parents deserves further investigation comparing adolescent responses with parent responses. Evaluating positive and negative religious coping is a significant component in understanding the relationship between spirituality, religiosity, and health outcomes. The patterns of religious coping have been described as either positive or negative. One study explored general religious coping but did not examine measures of positive and negative religious coping as they relates to health care utilization (O'Connell-Edwards et al., 2009). Two studies examined positive and negative religious coping (Bediako, 2011; Cotton et al., 2009). Positive religious coping was predictive of fewer hospital admissions (Bediako, 2011). Participants reported more instances of positive religious coping than negative religious coping (Bediako, 2011; Cotton et al., 2009). The current study is a qualitative design with an aim of providing adolescents a voice in describing their experiences. Information gained can provide guidance for future studies inclusive of parents. A qualitative study designed to compare adolescents' descriptions of their coping patterns with their parents' perception is warranted.

Summary of Gaps in the Literature

The previous sections described research conducted on spirituality and religiosity as elements in adolescents living with SCD. This section will provide a critique on gaps in the research and issues with the quality of studies completed. The body of literature addressing spirituality and religiosity in adolescents with SCD is limited. Most of the articles reviewed were associated with the SCD population and practices, not nursing

care specifically. Paucity in the literature will be addressed and includes the following topics: restricted populations, demographic data, terminology, limited assessment of the adolescent/parent dyad, limitations in methods and spirituality/religiosity, evaluating positive and negative coping, and comparisons between adolescent and adult research.

Restricted Populations

There are few studies addressing spirituality and religiosity in the SCD population. Moreover, this limited body of research, is skewed towards children and adolescents under age 14 and adults. Four studies reviewed addressed spirituality and religiosity in adolescents with SCD (Anie et al., 2002; Cotton et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). Only one of the studies addressed the adolescent population specifically (Cotton et al., 2009), and three of the four studies addressed spirituality and religiosity with both children and adolescents under 14 (Anie et. al 2002; Sibinga et al., 2006; Yoon & Black, 2006). One study was conducted on children aged 10 years and younger, and all other studies encompassing SCD were conducted on adults (Cotton et al., 2012). Most of the articles addressed SCD in the African-American population residing in the United States (Bediako et al, 2011; Cooper-Effa, 2001; Cotton et al., 2009; Cotton et al., 2012; Harrison et al., 2005; Mann-Jiles & Lynn-Morris 2009; O'Connell-Edwards et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). All of the results cannot be generalized to the world population of adolescents living with SCD. In addition, research was conducted with small convenience samples so results cannot be generalized to the entire population (Anie et al., 2002; Bediako et al., 2011; Cooper-Effa et al., 2001; Cotton et al., 2009; Harrison et al., 2009; Mann-Jiles & Lynn-Morris, 2009; Sibinga et al., 2006; & Yoon & Black, 2006).

Demographic Data

Research conducted with the pediatric and adult populations did not specify

religious affiliations of the study participants as a scope of the demographic data (Anie et

al., 2002; Cooper-Effa et al., 2001; Cotton et al., 2009; Gil et al., 2004; Harrison et al.,

2009; Mann-Jiles & Lynn-Morris, 2009; Sibinga et al., 2006; Yoon & Black, 2006).

Further research could explore the level of diversity in religious affiliation and the

influence on health and illness. Two of the studies did not specify racial demographics of

the study participants and therefore could not be evaluated for inclusion of a diverse

population (Anie et al., 2002; Cooper-Effa et al., 2001). The current study does examine

religious affiliation and ethnicity as part of the demographic data.

Definitions and Terms

Limitations of the available research included inconsistent definitions, lack of

connection of use of spiritual and religious practices to outcomes, lack of data from

children and adolescents themselves, and limited generalizability. In two studies, prayer

and spiritual healing were explored but not defined (Sibinga et al., 2006; Yoon & Black,

2006). Praying and hoping were combined as an active coping strategy with no definition

of terms whether as separate concepts or as a combined concept (Anie et al., 2002). Lack

of definitions and combining concepts may impede understanding of how each is relevant

to coping with SCD. Lack of definitions for spiritual and religious strategies when

describing parental use of alternative therapies may impede the understanding of

concepts and any existing correlations between the use of spiritual and religious strategies

and coping with SCD.

Adolescent/Parent Dyad

Questionnaires or diaries were used in the research studies and administered/provided to the parents (Sibinga et al., 2006; Yoon & Black, 2006), both the parent and the adolescent/child (Anie et al., 2002; Cotton et al., 2009), or the child alone (Cotton et al., 2012). Data from children or adolescents with SCD were not always obtained, which limits how this research may be translated into practice (Sibinga et al., 2006; Yoon & Black, 2006). Understanding why adolescents report higher levels of negative religious coping than parents/guardians may likely assist caregivers and pediatric providers in supporting adolescents. Research addressing the adolescent population living with SCD specifically and obtaining their perspectives is warranted. Finally, the studies reviewed used convenience sampling, which limits generalizability.

The desire of parents and guardians to discuss spiritual and religious practices with their health care providers was not addressed. Children's opinions on preferences for spiritual and religious strategies as types of alternative therapies were not provided, but may complement parental reports and guide further inquiry (Sibinga et al., 2006; Yoon & Black, 2006).

Two studies inquiring about experiences from the parents, did not comprise the perspective of the child/adolescent. Surveying the parents provided invaluable information, but surveying the pediatric population, would enhance the data and allow comparisons to be made between both perspectives. Assessing the coping process for adolescents and their parents may provide insight on how to address the needs of the family using a system approach. This can directly impact the adolescent's coping process.

Methods, Spirituality, and Religiosity

In order to understand the spiritual and religious elements of the adolescent, developing assessment tools considerate of their developmental nature is critical. Researchers for one study noted completing an assessment of the psychometric properties for the RCOPE that was used with the adult population (Bediako, 2011). Reliability and validity of the RCOPE or FACIT-Sp in adolescents was not described in a mixed method study (Cotton et al., 2009). To the knowledge of this researcher, the psychometric properties of the RCOPE for use in adolescents with SCD have not been evaluated. The psychometric properties for use of the FACIT-Sp in adolescents under 18 years of age have not been established. In addition, the psychometric tools for evaluating spirituality and religiosity, specifically in the adolescent population, have not been developed and used in adolescents with SCD.

There were no longitudinal studies identified, making it complicated to evaluate the influence of spirituality and religiosity using a developmental context. In addition, the ability to observe relational influence of spirituality and religiosity for adolescents over time is not possible with cross-sectional studies.

One study assessed church attendance in adults as a study variable (O'Connell-Edwards et al., 2009) and one assessed church attendance in adolescents (Cotton et al., 2009). Further appraisal of church attendance as a study variable and the relevance to coping for adolescents specifically is needed. This can provide meaningful insight into understanding the mechanisms by which spirituality and religiosity influence coping and offer developmental considerations.

One study using a mixed-method approach to research was reviewed (Cotton et

al., 2009), and a second study used a qualitative design (Cotton et al., 2012). The

qualitative data provided an understanding of how adolescents/children viewed God, as

well as the manner in which they used spirituality and religiosity to cope with SCD.

Remaining studies used a quantitative method to conduct research. In order to explore the

concept of spirituality and religiosity for adolescents, using qualitative methods can

provide meaningful insight. Qualitative studies along with quantitative studies can inform

researchers and provide direction for future research. In a comprehensive review of the

literature, only two studies involving qualitative methods for research with adolescents

and/or children with SCD were identified (Cotton et al., 2009; Cotton et al., 2012). There

is no study to date in which qualitative methods are distinctly used to examine spirituality

and religiosity in adolescents with SCD. The current study purports to directly explore

adolescents' descriptions of spirituality and religiosity. Conducting a qualitative study

will add to the current body of literature.

Comparisons Between Adolescent and Adult Research

Addressing pain specifically as a symptom of SCD and the relevance to

spirituality and religiosity were more common in the studies conducted with adults to

include adolescents aged 18 to 21 years (Cooper-Effa et al., 2001; Harrison et al., 2005;

O'Connell-Edwards et al., 2009). One pediatric study examined pain in relation to coping

(Anie et al., 2001) and one other pediatric study examined the number of pain crises

experienced in a year (Sibinga et al., 2006). No pediatric studies assessed pain severity in

relation to spirituality and religiosity. Two pediatric studies were designed to address

general symptom management and coping with SCD; and were based on the perspectives

of parents alone (Sibinga et al., 2006; Yoon & Black, 2006). There were two studies that

addressed pain as a symptom of SCD, and the use of alternative strategies to include

spirituality and religiosity in coping with pain in children and adolescents (Sibinga et al.,

2006; Yoon & Black, 2006). Greater understanding of the use of spiritual and religious

strategies in relation to coping with pain and other challenges experienced by adolescents

with SCD is vital.

While the findings from research completed with adults may have bearing on the

adolescent population, broad generalizations cannot be made. Combining child and

adolescent populations may generate findings that are confounding. The cognitive

differences between the two populations may contribute to varied understanding of

concepts presented. As noted in the study completed with adolescents alone (Cotton, et

al., 2009), adolescents indicated experiencing more negative religious coping than their

parents. Evaluating the spirituality and religiosity of adolescents can offer information

specific to their life experiences. Spiritual and religious beliefs of parents have influence

on their children, but during adolescence a number of changes take place. Adolescents

seek to establish their sense of identity, and during these developmental transitions, their

spiritual and religious preferences may or may not resemble the spiritual and religious

preferences of their parents.

The relationship of spiritual and religious practices to health outcomes and service

utilization in adults was discussed (Anie et al., 2002; Bediako et al., 2011). Positive

religious coping was related to fewer hospital admissions in adults (Bediako et al., 2011).

In this study, hospital admissions was used as an objective study variable to better

represent severe pain as opposed to using subjective reports of pain. Results from one

pediatric study revealed that active coping strategies were related to increased use of

health utilization (Anie et al., 2001). The researchers suggest that hospitalization may be part of the active coping process. The increased readmission rate of hospital admissions for those with SCD in comparison to other chronic disease populations affirms the need to further explore the effects of spiritual and religious coping strategies on health care utilization (Elixhauser & Steiner, 2013). Continuing this research within the adolescent population will inform researchers and allow for specific needs to be addressed in the health care setting. Further exploring the association of spirituality and religiosity to pain severity, coping styles, and health care utilization will provide direction for future research. Addressing differences between adolescent and adult populations may assist providers in refining interventions to avoid hospital readmissions and impact the readmission rate across the lifespan.

Quality of life was studied in one study for adolescents (Cotton et al., 2009) and two studies for adults with findings supporting the relationship between spirituality and their perception of QOL (Adegbola, 2011; Mann-Jiles & Lynn Morris, 2009). The studies conducted with adults used two different QOL instruments. One researcher discussed the Quality of Life Scale as an instrument constructed in consideration of diversity (Mann-Jiles & Lynn-Morris, 2009). For the study conducted with adolescents there was a relationship between spirituality and school performance (Cotton, et al., 2009). School performance is one item used to assess health related quality of life in the younger population. School functioning which includes relationships with peers, is significant for adolescents. Variables perceived to enhance QOL for adolescents may exhibit some similarities, as well as differences when compared to adults. Examining the relationship between QOL variables with spirituality and religiosity in adolescents is warranted in

order to provide care that is developmentally appropriate.

Spirituality and religiosity were associated with managing the pain experiences of children, adolescents, and adults living with SCD (Anie et al., 2002; Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009). Most adults aged 18 and older exhibited moderate to high levels of spirituality and religiosity (Adegbola, 2011; Bediako et al., 2011; Cooper-Effa et al., 2001; Harrison et al., 2005; Mann-Jiles & Lynn Morris, 2009; O'Connell-Edwards, 2009). Spiritual and religious practices including church attendance and moderate frequency of prayer were associated with the lowest scores for pain severity and lower levels of anxiety and hostility in adults (Harrison et al., 2005; O'Connell-Edwards et al., 2009). Additional research exploring spiritual and religious coping strategies as modulating factors for pain experiences in adolescents is warranted.

Overall, 11 articles were examined in order to report on the state of the literature addressing spirituality and religiosity in children and adolescents with SCD, and provide insight to health care providers caring for this population. Drawing upon spiritual and religious beliefs to manage symptoms and cope with SCD was common among children, adolescents, and parents/guardians of children with SCD (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2006; Yoon & Black, 2006). Filling the gaps in the literature to support understanding of spirituality and religiosity in adolescents is crucial. Identifying best practices to evaluate spiritual and religious needs and provide holistic care that is developmentally appropriate is essential to their quality of life.

Adolescents and Vulnerable Population Considerations

Adolescents affected by social, political, and economic inequalities are especially

vulnerable to issues affecting their health. In the U.S., approximately two out of five

African-American children and one in three Hispanic children is poor (annual income

below $22,050 for a four-person family) and more than one in six African-American

children and one in seven Hispanic children lives in extreme poverty (annual income

below $11,025 for a four-person family) (Children's Defense Fund, 2009; U.S Census

Bureau, 2013). Poverty, historical inequities in health care delivery, institutional

discrimination, and provision of culturally incompetent health care contribute to poorer

health for minority children (Dunston, 2006). Well-being encompasses a general

satisfaction with life and being physically and mentally healthy and functioning

(Veehoven, 2008). Contributors of poor well-being may directly affect the health status

of children and adolescents leading to deficits in nutritional intake, exposure to

environmental hazards, developmental deficits, inadequate access to health care, stress,

unhealthy standards of living, intentional and unintentional accidents, underutilization of

health resources, and numerous medical diagnoses (Dunston, 2006).

The issues of poverty, inequities, and disparities affect African-American children

and adolescents. They are placed in unfavorable situations in which health disparities are

evident. For the child or adolescent living with SCD, the health disparities are cumulative

as this population deals not only with inequalities faced by children, adolescents, and

African Americans, but also with additional concerns that are unique to the SCD

population. The medical coverage for many patients with SCD is generally inadequate

due to lack of employment and being poor (Woods & Ballas, 2006). Multiple visits to

providers are generally warranted. Many providers are not specialized enough to care for

SCD patients, not interested in the population, or both (Woods & Ballas, 2006).

Disparities in health care leads to undue afflictions and inadequate outcomes for the patient with SCD. It is an injustice to ignore the magnitude of disparities experienced by this population.

When assessing vulnerability, aspects to consider include: perception, social and human capacity, power/autonomy, access to resources, protective mechanisms, and socioeconomic status (Aday, 1994). A review of the research for content on vulnerability in the SCD population shows a modest amount of explicit information pertaining to the vulnerable subject. Negative perceptions of pain and the pain experience were correlated with spiritual and religious methods of coping. Extrinsic religiosity to include church attendance was associated with lower scores on pain measures suggesting that perception of the experience does affect the illness outcome (Harrison et al., 2005). A negative perception of circumstances in particular is likely to make an individual more vulnerable to experience adverse outcomes emotionally, mentally, and physically (Griffin & Chen, 2006; Lupien, King, Meaney, & McEwen, 2001). Issues surrounding quality of life which that would encompass human and social capital were mentioned in the literature (Anie et al., 2002; Cotton et al., 2009). The literature suggests that SCD directly affects quality of life in relation to self and others.

The adolescent with SCD has more than one factor affecting autonomy and is considered to be doubly vulnerable (Moore & Miller, 1999). One issue of autonomy is being considered a minor who remains dependent, to a certain degree on the parents when faced with life decisions. Another factor affecting autonomy is living with a chronic illness and having an altered physiological status (Moore & Miller, 1999). Inequalities in access to care and continuum of care often faced by this population are not

generally addressed in the literature. When considering SCD, the impact of socioeconomic status on the illness trajectory is not usually incorporated. Socioeconomic status and effects which are unfavorable for adolescents usually have a negative impact on health outcomes (Lupien et al., 2001; Miller & Chen, 2007). When considering protective mechanisms, spirituality and religiosity are viewed as coping mechanisms worthy of future investigation (Anie et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga et al., 2005; Yoon & Black, 2006).

Spiritual development may be more significant for more vulnerable youth in comparison to those who are less vulnerable. For adolescents experiencing physical, mental, and emotional challenges, spiritual development can foster resilience in complex situations. The period during adolescence is a particularly formative time for spiritual development (Benson & Roehlkepartain, 2008). Framing spirituality as a developmental process that occurs for all persons regardless of their religious beliefs allows one's spiritual and religious preferences to be an integral part of understanding spiritual development. For adolescents who usually follow the traditions of their family initially, giving attention to beliefs viewed as essential are significant for health care providers to consider when conducting assessments, making decisions, and creating interventions. For adolescents or families who may not have an established spiritual or religious belief system, assessing where the family is and providing appropriate interventions to address their needs may be warranted.

Summary

Living with a debilitating disease like SCD is a challenging experience for all people diagnosed as well as their caregivers and families. Spirituality and religiosity are

demonstrated to be relevant concepts for the SCD population. Individuals use their spirituality and religiosity to assist them in managing daily life events encountered as a result of SCD. Parents and caregivers also use their spirituality and religiosity as integral components of routine practices to support themselves in managing the disease for their child or adolescent.

SCD has varying levels of severity. Further investigation to identify the relationship with the severity of the disease and participation in the use of spiritual and religious practices is essential in developing assessment techniques and appropriate care interventions for adolescents with SCD. Identifying the differences in how spirituality and religiosity are described and incorporated in daily experiences will allow health care providers to individualize interventions that will meet spiritual and religious needs of their adolescent patients as well as promote spiritual development.

Persons with SCD often lack the resources and financial support necessary to access adequate care in comparison to other populations living with a chronic illness. By exploring spirituality and religiosity in the context of living with SCD, the information can assist health care providers in identifying potential resources and spiritual strengths the individual can draw from and use to manage the disease. Understanding the influence of spirituality and religiosity on illness and health outcomes for the adolescent, including coping strategies, will assist in individualizing care from a developmentally appropriate perspective.

Health providers can assist children and adolescents in managing their unique spiritual concerns, and develop interventions to address their spiritual needs. This involvement is a step towards promoting effective coping strategies to ameliorate

symptoms of SCD and improve quality of life. Addressing inequalities in care is initiated

when health care providers explore factors unique for each pediatric patient and concepts

that are significant for the population to incorporate into the plan of care.

A qualitative study designed specifically for adolescents with SCD to describe

spirituality and religiosity is needed to provide rich data from the perspective of

adolescents. The data will inform researchers and provide a basis for designing future

research studies addressing the needs and concerns for this population.

Assumptions

The assumptions for the current study include:

1. The use of semi-structured interviews in adolescents with SCD will provide
   insight into their experiences as they describe their spirituality and religiosity.
2. Adolescents will describe their experiences truthfully.
3. Living with a chronic illness such as SCD is a subjective experience.
4. The experiences of adolescents with SCD are embedded in the processes of
   spiritual development and interrelated concepts.
5. **Spiritual development does not take place without consideration of other
   domains and concepts shaped by individual experiences.**

Research Questions

The research questions for the current study are:

1. How do adolescents living with sickle cell disease describe spirituality and
   religiosity?
2. What is the process of spiritual and religious development like for adolescents

with sickle cell disease?

3. What is the role of spirituality and religiosity in shaping beliefs about health

    and illness for adolescents with sickle cell disease?

CHAPTER THREE

Research Design and Methodology

Chapter three outlines the methods that were used to discover how adolescents with SCD describe spirituality and religiosity. A qualitative descriptive research design was used (Sandelowski, 2000). Gaining an in-depth perspective from adolescents provided rich and insightful data that can be used to improve conditions and interventions for this population. When researchers conduct descriptive qualitative studies, low-inference descriptions are generated, providing accurate accounts of experiences (Sandelowski, 2000). An aim of the current study was to obtain direct descriptions of phenomena as described by adolescents with SCD.

Recruitment Sites

All of the participants in the current study were recruited from a Comprehensive Sickle Cell Center at a pediatric hospital clinic and a SCD support organization in the community. Both recruitment sites are located in a large midwestern city in the United States. The Comprehensive Sickle Cell Center aims to assist clients in managing SCD and preventing complications. The center offers a clinic for clients taking hydroxyurea, routine clinic appointments, transfusion services, and routine screening for the risk of stroke. During routine clinic appointments, a clinical social worker, nurse clinician, physician, geneticist, and clinical psychologist follow clients. In addition, the program provides activities such as a parent network, community education and outreach, annual social activities, scholastic programs, and a program for transitioning patients to adult care. The support organization provides a coordinated approach to addressing issues

related to SCD to include educational campaigns, case management, and psychosocial
support for individuals and families affected by SCD.

Recruitment Procedures

An information session was scheduled with staff at the hospital and a session was
scheduled with staff at the support organization. The principal investigator (PI) provided
training in recruitment procedures to staff at both sites. The PI or the staff at the clinic
and support organization distributed an informational letter (Appendix A for participant
and Appendix B for parent) describing the current study to eligible adolescents and their
parents during their scheduled clinic appointments or monthly support group meeting.
When the PI was not on site, potential participants were informed that the PI could
contact them to discuss the current study or they could contact the PI directly. If
interested, they provided their name and contact information. The PI's contact number
was listed on the informational letters. If adolescents or parents requested additional
information, staff at the hospital or support organization notified the PI. Additional
questions were answered, and information about the study was provided upon request.
Recruitment continued at both sites until there was saturation of data. After participants
were contacted and the second interview was completed, contact information was
deleted.

Participants

A convenience sampling approach was used for prospective participants.
Convenience sampling was used in order to recruit sufficient participants for the
proposed research and analysis.

Inclusion criteria included: (a) participants with a diagnosis of sickle cell disease, (b) participants who were English-speaking, (c) participants were between the ages of 15 and 19 years. Exclusion criteria included (a) presence of a significant cognitive delay or communication impairment that would prevent interview participation, (b) current active acute episode of pain, or (c) experiencing other urgent medical crisis. Adult participants were eligible for the current research study upon meeting the following criteria: (a) they were the parent or legal guardian of an adolescent with SCD who participated in this study, (b) they were English-speaking, and (c) they were between the ages of 25 and 70 years.

Parental Consent and Adolescent Assent Process

Parental consent and adolescent assent (Appendix C and Appendix D for the support organization, and Appendix F and Appendix G for the hospital clinic) were obtained for adolescents under the age of 18 prior to participation in the current study. After presenting information about the current study, each parent was allowed time to read the consent form (see Appendix C for the support organization or F for the hospital clinic). If there were any questions, answers were provided. Confidentiality was explained at the time of obtaining the consent. Data were not shared with parents but would have been shared in the event that abuse was disclosed. In that case, the parent would have been notified and a report to child protective services would have been made. Demographic data were collected from parents of adolescents in the current study. Information regarding collection of demographic data was listed on the parent consent form and was required from parents for their participation in the current study.

Assent was obtained for all participants aged 15 to 17 years (Appendix D for the

support organization or G for the hospital clinic). Participants were assured in the presence of their parents that no information would be shared by anyone except in the case of child abuse, neglect, or concern for harm. Participants were also assured that their decision to participate or not participate in the current study would not affect the care they received. Participants were informed that the research was separate from the services they received at the clinic or support organization. Confidentiality and the option to withdraw from the current study at any time were stated and included in information on the consent form. Attention was given to the role of the parent during the assent process for verbal or non-verbal parental coercion. If any signs of coercion were to be observed, the PI would have informed the parent that the participant was not allowed to participate in the research study.

A copy of the consent was given to each family and included the names, addresses, and phone numbers of contact persons from the university the researcher attends. For participants recruited at the hospital, hospital contact numbers were included per research protocol should the family have any concerns or complaints about participation in the current study.

Consent was obtained for all participants aged 18 to 19 years (Appendix E for the support organization or H for the hospital clinic). In the case of abuse or neglect the PI would have discussed the event with the participant and facilitated reporting as needed. Participants were assured that their decision to participate or not participate in the current study would not affect the care they received. Participants were informed that the research was separate from the services they received at the hospital clinic or support organization. Confidentiality and the option to withdraw from the current study at any

time were stated and included in information on the consent form. Consent was obtained prior to the first interview for each participant.

Protection of Human Subjects

Protection of human subjects approval was obtained from the Institutional Review Board for the Protection of Human Subjects at Marquette University and Lurie Children's Hospital in Chicago. Demographic data collection complied with HIPAA requirements to ensure patient confidentiality and prevent dissemination of sensitive personal information.

The risk to participants in this current study was minimal. Given that the current study participants were adolescents, the PI was careful to clarify and answer questions or concerns of the participants. An identification number was created and used on all interview transcripts to protect identity. The first interview was labeled with the date, participant number, and "A," and the second interview was labeled with the date, participant number, and "B." De-identified interview transcripts and demographic data remained confidential by using password protection of all computer files. No protected information was abstracted from the hospital clinic medical records or provided by the hospital clinic staff. Once consent forms were signed, and participant name and identification number were validated with the participants' self-reported demographic surveys, participants' codes on the forms were used.

Strict confidentiality was maintained throughout the current study. Once consent forms were signed, the participant's name and identification number were validated with the participant's demographics and personal information. Participant codes were used on all of the forms. Participants' names were not entered into the data software, only the

coded number.

There were some potential risks to participants. Due to the personal nature of the interview questions, some of the participants could have found some of the questions to be emotionally upsetting. Participants did not have to answer any questions that made them feel uncomfortable. There were also potential benefits of participation. Exploring spirituality and religiosity among adolescents with SCD may provide a significant contribution to the current body of research. Results of the current study may contribute to raising consciousness, enhancing knowledge of health care providers, and possibly decreasing the discomfort experienced by adolescents with SCD. There were no intended direct benefits to participants, although they may have enjoyed the interview process and value that their contribution may help other persons with SCD.

A list with participant names, contact information, and unique patient identifier were stored in a locked cabinet for the purpose of tracking and contacting the participant from the first to the second interview. Upon completion of the study, the list was shredded. Only identification numbers were used on all interview transcripts so that the PI was unable to associate participants to their responses and questions. All de-identified interview transcripts and demographic data remained confidential by using password protection of all computer files. Once consent forms were signed and participant name and identification number were validated with the participant's self-reported demographics survey, participant codes were used on all of the forms. Strict confidentiality was maintained throughout the study.

Participants' names were not entered into the data software, only the coded number. During the study, participants' information was downloaded into a password-

protected file on the PI's computer. A transcriptionist professionally transcribed participants' interviews. Transcripts of the interviews were labeled with the participants' assigned number and included dates of the interviews. The first interview was labeled with the participants' assigned number and "A" with date of interview, and the second interview was labeled with the participants' assigned number and "B" with date of interview.

Consent forms and demographic surveys were kept in a locked file cabinet in the office of the PI. Consent forms and demographic surveys will be destroyed after five years. Digital recordings were downloaded to a password-protected file on the PI's computer and erased from the recording device. Digital recordings were deleted upon completion of the research project. De-identified data and transcripts will be kept indefinitely in a password-protected file of the PI, and may be used for future research or student instruction.

Data Collection and Plan for Data Management

This section describes the procedures that were used during data collection. Data was obtained from the Participant and Parent Demographic surveys, interviews with the adolescents, and observations during the interviews.

All participants, as well as a parent of the participant, completed a brief self-administered survey (Appendices I and J) for collecting basic demographic data prior to the interview process. A Participant Demographic Survey (Appendix I) was used to collect the following data: age, ethnicity, gender, year in school, work status, hemoglobinopathy (SCD type), disease severity, health history, religious affiliation, and denomination.

A Parent Demographic Survey (Appendix J) was used to collect the following data: age, ethnicity, number of children, ages of children, relationship to participant, number of children with SCD, parent with SCD, parent denomination, parent's religious affiliation, frequency of church attendance, level of education completed, marital status, and work status. The Participant and Parent Demographic Surveys were used to describe the participants and parents. The demographic surveys were completed after obtaining assent and consent. The parent was given an opportunity to review demographic data obtained from the participant for accuracy. Assistance was provided to participants and parents to complete the demographic surveys as needed. If assistance was needed, the PI verified with participants and parents that the information documented was accurate.

Qualitative data were collected by semi-structured interviews. An interview guide was used during the interview. There were two interview guides; one was used for participants indicating that they had religious beliefs (Appendix K) and a second guide was used for participants who indicated not having religious beliefs (Appendix L). The guide was used to explore the experiences of the adolescents. The interview guide was developed specifically for use in conducting the one-on-one semi-structured interviews. The guide consisted of 24 open-ended main questions accompanied by additional probes. Approximately 12 questions on the interview guide were asked during the first interview and approximately 12 questions were asked during the second interview. The guide was used as a reference for asking questions and when the participant appeared to be done addressing a specific topic. The questions in the interview guide were divided into three primary fields of inquiry, including: (a) general information about the participant, (b) spiritual and religious beliefs, and (c) how the participant's spiritual and religious beliefs

influence their life and health.

The principal investigator initially wrote the interview questions. Expert qualitative researchers with experience in pediatric and psychiatric nursing, a parish nurse, a social worker, and a minister reviewed the questions. Two adolescents served as content reviewers and evaluated the interview questions for understanding, clarity, and that the questions worked as intended. Dr. Harold Koenig, a researcher with expertise in spirituality, religion, and health, also reviewed the guides. Revisions were made to the interview guide as indicated by the reviewers prior to conducting interviews with the participants.

The interview consisted of two sessions in order to allow time to answer all of the questions. The participant code number was stated at the beginning of each interview. Participants were asked identical questions in the same sequence, although the follow up questions and degree of probing by the interviewer on key responses did vary. At the end of each question, main points were reviewed to validate the answers with the adolescents. After the first interview, an appointment was scheduled for the second interview. Bus transportation cards were offered if participants needed support to be present for the second interview.

After each interview, observations of the adolescent's nonverbal activity were recorded. The PI recorded field notes on a template for each participant. Information documented included date, setting, appearance of the participant, affect of the participant, and thoughts of the PI. Time for completion of forms was approximately five minutes for the demographic survey: and approximately one-and-a-half to two hours total for the semi-structured interviews, which were divided into two interviews. Time for completion

of demographic data and interviews was two hours total.

Data collection took place in a private room within the hospital clinic or the support organization office. If the participant or participant and parent agreed to participate in the current study, an attempt was made to conduct the first interview the same day if the PI was on site. If interviewing the same day was not an option, an appointment was scheduled for the first interview. The participants were reminded of the interview by phone one to three days before each appointment. If the parent accompanied the adolescent, the parent was asked to wait in the waiting area to ensure privacy for the participant during the interview.

The PI established rapport with the adolescents in the first interview in order to create a comfortable environment for responding to the interview questions. Time between the first and second interview allowed the adolescents time to reflect on the questions and develop their thoughts as needed to verbalize their responses. The second interview was scheduled within a one to four-week time frame when possible with five participants. The second interview was scheduled five to seven months after the first interview for four participants, as it was more convenient to return during a scheduled appointment. A standard digital recorder was used to record all of the interviews. All of the interviews were transcribed verbatim. A transcript was completed for each interview by a professional transcriptionist. Transcripts of the interviews were labeled with the participant's assigned number and included dates of the interviews. Once the transcripts were completed, the PI read each transcript while listening to the digitally recorded interview to ensure accuracy of the transcription, insert missing or misinterpreted words, delete identifiers, and gain a gestalt of the interviews.

Each staff person and participant were informed that a Visa gift card in the amount of $25 would be provided upon completion of the first interview, and a gift card in the amount of $25 would be provided upon completion of the second interview. To encourage voluntary participation, the adolescents were informed about the stipends after they expressed an interest in participating in the current study. The adolescents were informed that if they felt uncomfortable or demonstrated signs of spiritual or emotional distress during the interview, the adolescents would be able to pause during the interview to discuss their emotions, could decide to skip the question, and return to it later, or omit the question from the interview.

Data Analysis

The PI developed a field note guide for use during data collection. The guide consisted of three sections, including: (a) observation notes, (b) methodological notes, and (c) theoretical notes (Denzin & Lincoln, 1998). Observation notes consisted of details of what the PI saw and heard before, during, and after the interviews. Methodological notes consisted of messages the PI created regarding how to collect the data. Examples of methodological notes included whom to contact, when to contact, what to wear, and changes made during the process. Theoretical notes consisted of the PI's thoughts, hypotheses, and critiques. The critiques were of the PI's actions, thoughts, and observations. Theoretical notes assisted the PI in remaining open and receptive to alternative interpretations. These notes were maintained as part of the audit trail.

Descriptive analysis of demographic data was conducted to generate summary information for each participant and parent, and describe the group of participants. Data analysis consisted of three phases, including data reduction, data display, and

conclusion drawing and verification (Miles & Huberman, 1994). During data reduction, a process of selecting, focusing, simplifying, abstracting, and transforming data from the participants' transcriptions and PI's field notes was used (Miles & Huberman, 1994). Data reduction was continuous throughout the analysis process.

The entire interview transcript and field notes for each participant were entered into NVivo 10 for analysis. Transcripts were labeled with the participant number and interview number ("A" for first interview or "B" for second interview). An initial coding template was developed to code each transcript (Miller & Crabtree, 1992). The initial coding template included the three core developmental processes of spiritual development as described in the Spiritual Development Framework, including, (a) Awareness or Awakening, (b) Interconnecting and Belonging, and (c) A Way of Living. The template was used to begin coding the first interview transcript. Additional codes were added as they arose from the data. Data were paraphrased and further divided into smaller categories (with codes assigned within and across each category). Each category was identified with a code, and a summary was created for each code. Upon completion of coding the first interview transcript, the coding template included 13 codes. This template was applied to the second transcript (part two of the first interview). A second researcher independently coded the same two transcripts (both parts of the first interview) with the 13 codes on the template. Upon comparison of the coding of the PI and the researcher, approximately 80% of the coding matched. This coding process led to a revised list of 21 codes. At the end of each coding session, the PI reviewed codes, checked for redundancy, and combined codes to reduce data describing similar information and reorganized previous codes as needed. A copy of the codes from each

session was saved prior to changes made by the PI. As changes were made to the coding scheme, the date and time of the changes were documented in the memo section. Changes were documented in the methodological section of the field notes and used in maintaining an audit trail. This resulted in a final coding template of 24 codes (18 top-level codes and 6 sub-codes). This final template was applied to the remaining transcripts and is also included in Appendix M.

Coded data was displayed using summaries. The PI kept in mind that summaries may have been revised as analysis continued and maintained some flexibility. Conclusion-drawing and verification consisted of scanning the codes and summaries to generally review listed content and thematic analysis. Using thematic analysis, the PI looked within and across each code for relationships and identified themes. The themes were categorized further into specific phenomena and grouped into specific categories (Munhall, 2001). Codes identified reflected the framework concepts, research questions, interview questions, and identified themes that resulted from analysis of the data.

Content listed was revised, verified, and disconfirmed as needed after a more detailed evaluation. All conclusions were documented, explained, and written. Exemplars of conclusions were identified to present. References were made to previous transcripts to be sure conclusions were not reduced to simplicity. Conclusions were reached by understanding findings in relation to the framework and research questions.

Methodology and Rigor

Trustworthiness is used to establish and evaluate the worth of a qualitative study (Lincoln & Guba, 1985). As a primary step in contributing to the trustworthiness of the current research, the role of the PI was considered. The role of the PI was as an

instrument of data collection (Denzin & Lincoln, 2011). The PI is a middle-aged African-American female who has nursing experience working with the pediatric population in a health care organization and in a community health setting. The PI also has experience working in ministries serving children and adolescents. The PI identified personal experiences and views about spirituality/religiosity prior to interviewing participants by acknowledging professional and personal experiences, and documenting opinions throughout the data-collection process.

Trustworthiness was supported by an iterative review of interview data. In an effort to ensure trustworthiness, strategies included credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility is an evaluation of whether the research findings represent a credible analysis of the data. Techniques that were used to maintain credibility include prolonged engagement, respondent validation, and triangulation (Lincoln & Guba, 1985; Maxwell, 2005). Prolonged engagement involves spending enough time to understand the phenomenon of interest. The PI interviewed participants using a semi-structured approach on two separate occasions for up to a total of two hours. The time for completing two interviews per participant and arriving at saturation of data took 16 months. The PI completed interviews for nine participants within a 16-month time frame, allowing for *prolonged engagement* of the PI. This prolonged engagement allows time for building trust and rapport among participants. The interviews were transcribed verbatim and included what the PI considered to be significant. Notes were documented on observations made during the interview process.

Respondent validation took place by soliciting feedback and confirmation about

conclusions from participants during the interviews and upon conclusion of the interviews (Maxwell, 2005). The biases and misunderstandings of the PI were determined during reflection, after the first interview, and documenting relative notes in the theoretical section of the field guide. During the second interview, perceived misunderstandings of the PI were presented for clarification to participants, in order to lessen the possibility of misinterpreting their responses. After completing the second interview, two participants assisted the PI with clarification and confirmation of data analysis results.

Triangulation of data was used to increase credibility. Triangulation is established through use of different sources, methods, investigators, and theories (Lincoln & Guba, 1985). For the current study, more than one source was used to interview nine participants. Each participant was interviewed on two separate days and in some instances during two separate seasons of the year.

Transferability refers to the researcher providing a thorough description of the research findings (Lincoln & Guba, 1985). The description should allow other researchers to determine if results can be applied to other settings. A summary listing demographic data of all study participants is provided. Findings included thick descriptions presenting the context of participants' experiences. Thick descriptions include the purpose and significance attributed to each experience (Denzin & Lincoln, 1998).

Confirmability refers to the extent to which others can confirm the research (Lincoln & Guba, 1985). An audit trail was maintained throughout the current study and the analysis. The audit trail consisted of all documentation detailing observations made

during data collection, field notes, observation notes, methodological notes, theoretical notes, code descriptions, and themes as well as any revisions or changes to the code descriptions and categorization.

Dependability emphasizes the need for the researcher to take into consideration changes in the context (Lincoln & Guba, 1985). Coding checks were completed between the PI and another researcher using two separate participant transcripts. Use of an inquiry audit, identifying discrepant data, and making comparisons between participants was used to establish confirmability and dependability. The PI used an audit inquiry to include raw data (field notes and digital recordings), data analysis and reduction products (summaries), data reconstruction and synthesis products (thematic categories and synthesis), process notes (procedure and design strategies), and materials related to intentions and disposition (study proposal).

In addition, the PI identified discrepant data for analysis to support confirmability and dependability (Maxwell, 2005). This is data that the PI was unable to account for with a specific interpretation. In this case, the PI assessed whether to maintain or modify the conclusion. The PI identified all data that did not fit the conclusions made by the PI. Other qualitative researchers were asked to assist the PI in reviewing and evaluating discrepant content, allowing conclusions of discrepant data to be made. Discrepant data was reviewed, and maintained as not corresponding to conclusions or modified to fit conclusions made by the PI.

Limitations

The current study explored spirituality and religiosity in adolescents living with sickle cell disease. Participants were mostly Christian, religious, and represented

primarily one ethnic group. Information regarding adolescents' descriptions and

experiences of spirituality is therefore limited to a predominantly religious group.

Another potential limitation is response bias, if adolescents answered questions in a

manner they felt would please the PI. This would include the possibility that adolescents

withheld information from the PI. Finally, participants receive specialized care at a well-

supported sickle cell clinic and their experiences may differ from those who do not

receive similar care

**Spirituality and Religiosity as Coping Strategies for Adolescents
Living with Sickle Cell Disease:
A Review of the Literature**

Dora Clayton-Jones PhD(c)[1]

Kristin Haglund PhD[2]

[1]Corresponding Author; Marquette University, College of Nursing, P.O. Box 1881,

Milwaukee, WI 53201-1881; dora.jones@mu.edu; phone 414-219-9080

[2]Marquette University, College of Nursing, P.O. Box 1881, Milwaukee, WI 53201-1881;

kristin.haglund@mu.edu

Spirituality and Religiosity as Coping Strategies for Adolescents
Living with Sickle Cell Disease:
A Review of the Literature

Abstract

Abstract Sickle cell disease (SCD) is a serious debilitating chronic illness. Spirituality and/or religiosity (S/R) have been linked to improved coping and health outcomes for persons with SCD. Exploring S/R may lead to coping interventions to improve the quality of life (QOL) and health outcomes for adolescents. The aims of this literature review were to examine the associations of S/R in adolescents living with SCD and topics that have implications for clinical practice and future research. A comprehensive literature search was conducted using 7 electronic databases to find research articles on S/R and SCD among adolescents. Of the 85 studies retrieved, 11 articles between 2000 and 2014 met the inclusion criteria and were reviewed. Using S/R may be significant among adolescents coping with SCD and managing pain, impacting hospitalizations, and affecting QOL.

Keywords

Spirituality, religiosity, sickle cell disease

Sickle cell disease (SCD) is the most common autosomal recessive genetic

disease in the United States, affecting approximately 70,000 to 100,000 Americans

(National Institute of Health, 2012). An estimated 113,098 hospitalizations and over one

billion dollars in hospital costs are attributed to SCD annually (Steiner & Miller, 2006;

Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). The hospital 30-day readmission

rate for SCD is 31.9% and accounts for the highest readmission rate compared to all other

diagnoses, including heart or renal failure (Elixhauser & Steiner, 2013). SCD is a chronic

debilitating disease that affects many systems including cardiovascular, respiratory,

digestive, lymphatic, endocrine, reproductive, urinary, integumentary, musculoskeletal,

and the central nervous system (Pinckney & Stuart, 2004; Rees, Williams, & Gladwin,

2010; Weinblatt, 1998). Adolescents with SCD experience symptoms, treatments, and

complications of their condition that may hinder them in their physical, psychosocial,

emotional, and academic functioning. Symptoms and complications include pain, chronic

anemia, disability, organ damage, increased risk for infection, and early death

(Ignatavicus & Workman, 2006). Frequent hospitalizations are common for many

adolescents living with SCD. Limitations of the hospital environment including social

isolation and disruption of learning pose challenges to academic achievement and overall

development for adolescents.

Spirituality and religiosity (S/R) are elements of humanity that individuals often

draw from to cope with life challenges (Mahoney, Pendleton, & Ihrke, 2006; Pargament,

Koenig, Tarakeshwar, & Hahn, 2004). *Religiosity* refers to as a commitment to an

organized way of knowing and orienting one's self to the religious community's subject

of worship (Schaefer, 2010). *Spirituality* is the intrinsic capacity of human persons to

transcend themselves to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003). Sacred refers to a divine being, ultimate reality, or ultimate truth as perceived by the person (Larson, Sawyers, & McCullough, 1998).

When discussing religiosity, spirituality, and health, the emerging research of psychoneuroimmunology is of particular importance. Psychoneuroimmunology (PNI) is the study of how social and psychological factors affect the neuroendocrine and immune systems (Koenig & Cohen, 2002). The effects of psychological and physical stressors can have a negative effect on neuroendocrine and immune functioning, which can adversely affect the body's ability to resist disease. Stressors refer to the environmental demands placed on persons (Cohen, Kessler, & Gordon, 1995). Psychological stressors generally refer to emotional or mental demands such as anxiety, depression, or major life events. Physical stressors refer to demands placed on persons that impact the body such as lack of sleep, illness, or malnutrition. In studies of adults, spirituality and religiosity have been found to decrease stress and the negative effects of stress on the body (Lynn, Paris, Frye, & Schell, 2010; Mihaljević et al., 2011; Tartaro, Luecken, & Gunn, 2005). Adults may use spirituality and religiosity to assist them in managing stress, which may contribute to improved immune and physiological functioning (Dedert et al., 2004; Ironson et al., 2002; King et al., 2002; Lynn et al., 2010; Mihaljević et al., 2011; Tartaro et al., 2005). Researchers have found that stressors affect immune and physiological functioning in adolescents, however, little is known about how spirituality and religiosity can assist with managing stress in the pediatric population (Matthews, Salomon, Brady,

& Allen, 2003; Sandberg et al., 2000). The study of psychoneuroimmunology provides a

mechanism through which S/R interventions may lead to improved health outcomes for

this population.

The purpose of this literature review was to examine religion and spirituality

among the pediatric and adult populations living with a diagnosis of SCD. Consideration

of spirituality and religiosity may enlighten pediatric health care providers on the spiritual

elements of adolescents and allow for enhanced personalized care when constructing

interventions and evaluating outcomes.

Studies were included in this review if they met the following criteria: (a)

examined spirituality and/or religiosity (S/R) in adolescents and/or children with SCD;

(b) examined S/R among parents of adolescents and/or children with SCD; (c) examined

S/R in adults to include older adolescents aged 18-21; (d) were quantitative or qualitative

articles; and (e) were published in peer-reviewed journals. The databases searched were

Cumulative Index to Nursing and Allied Health Literature (CINAHL), Health Source

Nursing/Academic, ProQuest Health Module, PsycINFO, Medline, PubMed, and the

American Theological Library Association (ATLA). The search strategy used in this

review included the following string of terms: "sickle cell disease" + "spirit*" (for

spiritual or spirituality) + "adolescen*" (for adolescent, adolescents, or adolescence) or

"x…." The alternate term included the following: "children," "religio*" (for religion,

religious, or religiosity), "health," "pediatric," and "coping." This approach was

developed to search for all published data that researched S/R as elements of human

development for adolescents with SCD.

The subject heading algorithm utilized by CINAHL, Medline, and PsychInfo did

not completely extract search results that related to spirituality and/or religiosity and health outcomes. The search method also included searching the references of reviewed studies published on spirituality and/or religiosity (S/R) to include adolescents and/or children with SCD. Author searches were conducted to locate any studies in progress and to become informed with the background of the author. A total of 85 articles were retrieved. Eleven articles met the inclusion criteria and were included in this review.

Results

All 11 studies addressed S/R and SCD; one reported on S/R in children with SCD, three included adolescents and children with SCD, one included only adolescents with SCD, and six included adults 18 years and older (see Table 1). In reviewing the 11 studies, one main topic and four subtopics emerged. The main topic was spirituality and religiosity as sources for coping strategies. The subtopics included: (a) S/R coping strategies and pain management; (b) S/R coping strategies and health care utilization; (c) S/R coping strategies and quality of life; and (d) positive and negative religious coping.

Spirituality and religiosity as Sources for Coping Strategies

Two research articles discussed religious and spiritual practices used by parents of adolescents and children with SCD as an approach to coping and enhancing clinical care (Sibinga, Shindell, Casella, Duggan, & Wilson, 2006; Yoon & Black, 2006). Prayer and spiritual healing were identified as S/R strategies used most often by parents or guardians of children with SCD (Sibinga et al., 2006). Religious and spiritual practices were significant for caregivers who used them with their children or adolescents with SCD (Sibinga et al., 2006; Yoon & Black, 2006). Parents who used S/R practices with their

adolescents or children with SCD were interested in discussing alternative therapies with health care providers, or felt that S/R strategies would be helpful. While parents expressed a desired to review alternative therapies with providers, some felt providers were not interested (Sibinga et al., 2006). In one study, only one-third of respondents felt their providers were interested in S/R strategies (Yoon & Black, 2006).

The manner in which prayer helped with coping was not described in some of the studies (Anie, Stepsoe, Ball, Dick, & Smalling, 2002; Sibinga et al., 2006; Yoon & Black, 2006). Self-prayer and spiritual healing were used more frequently with adolescents and children who used two or more analgesics (Yoon & Black, 2006). Parents were more likely to use prayer and spiritual healing with their children who were older (mean ages of 9.7 years versus 6.4 years), had higher scores on SCD severity scale (OR 1.33, 95% CI 1.02, 1.72; $p = 0.03$), had a higher perceived impact of SCD on the child's life ("tremendous" versus "no" impact, $p = 0.02$), and multiple hospitalizations within the preceding 12 months ($p = 0.05$) (complete results of statistical tests for this study were not provided) (Sibinga et al., 2006). Parents who used prayer and spiritual healing for themselves and those who had a higher level of education were more likely to use prayer and spiritual healing with their SCD affected children.

Using a mixed methods approach (quantitative surveys and qualitative interviews), researchers in a study by Cotton et al. (2009) surveyed 48 adolescents with SCD and 42 parents about how they used S/R to cope with their illness. Of the 37 adolescents completing quantitative surveys, 35% ($n = 13$) prayed once or more daily for symptom management, 64% ($n = 24$) prayed a minimum of once per week, and 51% ($n = 19$) reported attending religious services a minimum of once per week (Cotton et al.,

2009). Using the FACIT-Sp to measure spirituality, adolescents demonstrated high levels of spirituality. Approximately 73% of adolescents ($n = 27$) asked for forgiveness of sins, 67% ($n = 25$) looked for a stronger connection with God/a Higher Power, and 64% (n=24) sought God's love and care. Positive religious coping encompasses elements that provide spiritual encouragement, an optimistic redefining of negative circumstances, and mutual religious coping between the individual and God (Pargament, 1997). Negative religious coping includes elements of religious pain, discontent with the congregation and/or God, and negative religious reframing (Pargament, 1997). Adolescents reported greater use of positive religious coping strategies than negative religious coping strategies (22% to 47% reported using each strategy "a great deal"). Parents also reported greater use of positive religious coping strategies than negative religious coping (29% to 62% reported using each strategy "a great deal"). Adolescents reported greater negative religious coping than nonmatched parents, $t(76) = -2.01$, $p < 0.05$. Eleven adolescents completed the qualitative interviews and all reported a belief in God. Adolescents described religion as guiding them when making decisions about whether to engage in risky behaviors. Adolescents indicated that having their parents pray was relevant. School functioning was positively associated with overall spirituality ($r = 0.57$, $p < 0.01$) (Cotton et al., 2009).

In another study of children with SCD, prayer was identified as a religious coping strategy used to cope with SCD. More than half of the children relied upon their religion to cope with SCD. Religious coping strategies included relying upon religion to manage and provide comfort when they were sick or in pain and give meaning during stressful events related to SCD (Cotton et al., 2012). Children described God as a functional God

(provided practical care), an emotional God (provided comfort when in pain), or both. A couple of the children reported being disappointed by God's response or lack of response to their illness. Prayer was a common coping strategy and religious methods for coping gave meaning when facing stressful experiences.

Spirituality and religiosity were used as a source of coping in adults inclusive of older adolescents from 18 to 21 years of age (Bediako et al., 2011; Cooper et al., 2001; Harrison et al., 2005; O'Connell et al., 2009). Praying, bible study, and church attendance were religious methods used for coping with SCD. Positive and negative religious coping were evaluated in one study (Bediako et al., 2011).

Adult studies focused on examining the association of spirituality and religiosity with specific outcomes rather than the manner in which spiritual and religious strategies were used (Harrison et al., 2005; O'Connell-Edwards et al., 2009). Types of spiritual and religious strategies used by adults were mentioned, but only generally described.

One pediatric study made reference to consideration of holistic care to include the biophysical, psychological, sociocultural, and spiritual elements of the person (Adegbola, 2011). Studies investigating the relationship between spirituality and religiosity with stress and physiologic functioning in adolescents are warranted. Adolescence can be a stressful stage of development and, when coupled with a severe chronic illness, the effects of stress can be complex. Identifying potential sources of support, to include religion and spirituality may offer guidance in establishing optimal health and well-being for adolescents with SCD. Resources that are identified as being helpful for adolescents may be a source of ongoing support during their adult years and merit exploring.

A definition of spirituality or religiosity was provided in one pediatric study

(Cotton et al., 2009) and in three studies inclusive of adults (Adegbola, 2011; Cooper-Effa et al., 2001; Mann-Jiles & Morris, 2009). In a pediatric study, religious coping was described (Cotton et al., 2012). Two studies discussed the relevance of spirituality or religiosity, but a definition was not presented (Bediako et al., 2011; Harrison et al., 2005). Consistent inclusion of defined concepts will aid in understanding the relationship between concepts and the impact on coping.

Religious and Spiritual Coping Strategies and Pain Management

In six studies, results indicated that S/R coping strategies were used to manage pain. Three studies addressed S/R coping strategies and pain management in adults (Cooper-Effa, Blount, Kaslow, Rothenberg, & Eckman, 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009), three studies addressed S/R coping strategies and pain management in adolescents and children (Anie et al., 2002; Sibinga et al., 2006; Yoon & Black, 2006). Caregivers used S/R coping strategies in caring for their SCD affected adolescents and children (Yoon & Black, 2006). In this quantitative, cross-sectional descriptive study, more than 70% of caregivers ($n = 44$) used some form of therapy such as prayer, spiritual healing by others, massage therapy, relaxation, administering megavitamins, or administering herbal products. Of these modalities, more than 70% of the caregivers used self-prayer, and over 50% utilized spiritual healing (Yoon & Black, 2006).

Adolescents and children with SCD used praying and hoping as coping strategies. Participants used praying and hoping more than all of the active coping strategies identified and utilized methods such as calming self-statements, diverting attention, and reinterpreting pain sensations (Anie et al., 2002). Adolescents and children may use

active coping to more effectively cope with SCD and their pain experiences. Adolescents

and children who used more passive adherence coping methods (resting,

heat/cold/massage, taking fluids) experienced more severe pain. Adolescents used S/R

strategies to manage their SCD. The S/R strategies that were used most often by

adolescents with SCD were prayer and spiritual healing (Cotton et al., 2009; Cotton et al.,

2012). Prayer and hoping were combined as one active coping strategy and the average

score for the use of prayer alone cannot be determined (Cotton et al., 2009). The

association of spiritual well-being with pain experiences was explored (Cooper-Effa et

al., 2001). The use of S/R coping strategies were associated with assisting one in coping

with the pain associated with SCD (Cooper-Effa et al., 2001) and decreased reports of

pain in adults (Harrison et al., 2005). Pain was identified as being a significant variable

when considering the association of spiritual and religious coping strategies (Anie et al.,

2002; Cooper-Effa et al., 2001; Cotton et al., 2009; Cotton et al., 2012; Harrison et al.,

2005; O'Connell-Edwards et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). The

association of spirituality with pain experiences was explored. Spiritual and religious

coping strategies were associated with decreased reports of pain (Cooper-Effa et al.,

2001; Harrison et al., 2005). Increased use of pain medication and SCD severity was

associated with greater use of spiritual and religious strategies (Sibinga et al., 2006; Yoon

& Black, 2006). A SCD severity scale included a health rating, measures of SCD pain,

hospitalizations, disease, and impact (Yoon & Black, 2006). While not assessed, the

presence of pain was included in the overall score for a type of quality of life (QOL)

survey (Adegbola, 2011; Cotton et al., 2009; Mann-Jiles & Morris, 2009). There was a

positive correlation between spirituality and QOL.

Spiritual and religious practices, including church attendance and moderate frequency of prayer, were associated with the lowest scores for pain severity in adults (Harrison et al., 2005; O'Connell-Edwards et al., 2009). Caregivers used spiritual and religious coping strategies more often in caring for their SCD affected adoelscents who were ≥ 13 years of age (Yoon & Black, 2006). The authors provided as possible explanations, parents being concerned about their adolescent's pain severity and employing more than one intervention, or concern over opioid use.

A study specifically examined hospital admissions in relation to religious coping rather than subjective responses such as pain severity (Bediako et al., 2011). This objective to build upon previous inquiry in researching the relationship between spirituality, religiosity, and SCD is valuable. By developing this initiative with ongoing follow-up on prior research, focused summaries for future studies, as well as consistent and timely evaluation of completed research, gaps in the literature can be reviewed and filled. Those with SCD frequently experienced pain crises as well as a multidimensional phenomenon affecting their QOL. Understanding the experiences of adolescents with SCD warrants a multidimensional approach to explore the use of spiritual and religious coping strategies.

Religious and Spiritual Coping Strategies and Health Care Utilization

Adolescents and children who responded to pain using active coping strategies (including spiritual and religious strategies) were more likely to be hospitalized (Anie et al., 2002). The authors indicated that seeking care from a hospital might be an example of their active coping strategies. The authors also concluded that hospital utilization was not predicted by their pain experiences.

Participants who indicated having had more experiences of positive religious coping demonstrated fewer hospitalizations over a 12-month period (Bediako et al., 2011). While sickle cell disease type was identified as a study variable, disease type is not a consistent indicator of pain severity. This may impact interpretation of the relationship between religious coping and hospital admissions. The authors do present a good argument that using religious activities as a study variable can be confusing in understanding the relationship of spirituality and religiosity to health outcomes. Two studies included as demographic data the number of hospitalizations or medical visits for participants in the year prior to the study (Cooper-Effa et al., 2001; Sibinga et al., 2006). This variable was used to determine disease severity and no associations were made with spiritual and religious coping and health care utilization.

Frequency of church attendance was directly associated with health care utilization, including number of hospitalizations and number of days in the hospital (O'Connell-Edwards et al., 2009). Low to moderate frequency church attendance was associated with better clinical outcomes and less health care utilization (O'Connell-Edwards et al., 2009). Evaluation of study results also indicated that the higher the frequency of church attendance, the higher the frequency of health care utilization. Analysis of data suggested that moderate frequency prayer had better outcomes in comparison to low or high extremes of prayer. This finding suggested that the complexity of illness might have caused individuals to rely more on their spiritual and religious coping strategies. It may also indicate that the more individuals relied on spiritual and religious coping strategies, the more likely they were to seek out health resources in general. Moderate frequency of prayer was associated with the highest frequency for

number of hospitalizations, number of days hospitalized, and emergency department visits. The authors suggested that there may be specific characteristics, such as healthy coping behaviors, of those engaged in moderate spiritual and religious coping strategies that caused them to utilize health care resources more often. This concept should be further explored.

Religious and Spiritual Coping Strategies and Quality of Life

In a pediatric study, spirituality was associated with enhanced life satisfaction and enhanced life direction (Cooper-Effa et al., 2001). The mechanism of this association is not clearly understood. In another previously mentioned study, Health Related Quality of Life (HRQOL) in adolescents with SCD was evaluated (Cotton et al., 2009). School performance was evaluated in relation to overall spirituality. Higher spirituality was associated with better school performance. Two quantitative descriptive studies examined the QOL in patients with SCD, aged 18 and older. The mean Quality of Life Scale score (QOLS) for healthy populations was 90, whereas for patients with sickle cell disease, the mean QOLS score was 83.6 (Mann-Jiles & Morris, 2009). QOL was directly related to the individual's perception of spirituality, t (59) = -2.970, $p < .05$ (Mann-Jiles & Morris, 2009). Those with higher levels of spirituality also had higher QOL scores. Study participants were more likely to focus on what gives meaning to their lives rather than religious routine and practices, specifically when considering QOL issues. In a second study in which QOL was explored, the relationship between QOL, spirituality, and self-efficacy were examined (Adegbola, 2011). There was a significant relationship between the perception of QOL and spirituality, r (88) = 0.68, $p < .05$.

Positive and Negative Religious Coping

The patterns of religious coping have been described as either positive or negative. Two studies examined positive and negative religious coping (Bediako et al., 2011; Cotton et al., 2009). Positive religious coping was predictive of fewer hospital admissions (Bediako et al., 2011). Participants reported more instances of positive religious coping than negative religious coping (Bediako et al., 2011; Cotton et al., 2009). One study examined religious coping in both adolescents and parents (Cotton et al., 2009). Adolescents used more negative coping strategies than their nonmatched parents. This observed difference between adolescents and their parents deserves further investigation. A qualitative study designed to compare adolescents' descriptions of their coping patterns with their parents' perception is warranted.

Discussion

Overall, 11 articles were examined in order to report on the state of the literature addressing S/R in adolescents with SCD and provide insight to pediatric providers caring for this population. Drawing upon religious and spiritual beliefs to manage symptoms and cope with SCD was common among adolescents, children, and parents/guardians of children with SCD (Anie et al., 2002; Cotton et al., 2009; Sibinga et al., 2006; Yoon & Black, 2006). One study assessed reports of pain for adolescents and children and their parents as well as coping to include S/R approaches (Anie et al., 2002).

Spirituality and/or religiosity were associated with managing the pain experiences of adolescents, children, and adults living with SCD (Anie et al., 2002; Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009). Most adults aged 18

and older exhibited moderate to high levels of spirituality and religiosity (Adegbola, 2011; Bediako et al., 2011; Cooper-Effa et al., 2001; Harrison et al., 2005; Mann-Jiles & Morris, 2009; O'Connell-Edwards, 2009). Religious and spiritual practices, including church attendance and moderate frequency of prayer, were associated with the lowest scores for pain severity and lower levels of anxiety and hostility (Harrison et al., 2005; O'Connell-Edwards et al., 2009).

Addressing pain specifically as a symptom of SCD and the relevance to spirituality and religiosity were more common in the studies conducted with adults aged 18 and older (Cooper-Effa et al., 2001; Harrison et al., 2005; O'Connell-Edwards et al., 2009). Two pediatric studies were designed to address general symptom management and coping with SCD and were based on the perspectives of parents alone (Sibinga et al., 2006; Yoon & Black, 2006). There were two studies that addressed pain as a symptom of SCD and the use of complementary and alternative methods to include S/R in coping with pain (Anie et al., 2002; Yoon & Black, 2006). Greater understanding of the use of S/R strategies to cope with pain in adolescents with SCD is needed.

The relationship of religious and spiritual practices to health outcomes and service utilization has been explored (Anie et al., 2002; Bediako et al., 2011). Positive religious coping was found to be related to fewer hospital admissions (Bediako et al., 2011); the authors suggest that readmission rate for those with SCD in comparison to other chronic disease populations affirms the need to further explore the effects of S/R coping strategies on health care utilization (Elixhauser & Steiner, 2013).

Quality of life (QOL) was examined in one study for adults aged 18 and older and one study in adolescents, with findings supporting the relationship between spirituality

and their perception of QOL (Adegbola, 2011; Mann-Jiles & Morris, 2009). One study

conducted with adolescents demonstrated a relationship between spirituality and school

performance (Cotton et al., 2009). School performance is one item used to assess health

related quality of life (HRQOL). Examining the relationship between QOL and

spirituality and religiosity in adolescents is warranted.

One study assessed church attendance in adolescents (Cotton et al., 2009) and two

studies assessed church attendance in adults (Harrison et al., 2005; O'Connell-Edwards et

al., 2009). Researchers discussed church attendance as a confounding variable in that

there may be individuals who are spiritual and religious, but due to a disability may not

be able to attend church service (Harrison et al., 2005). Additional assessment of church

attendance and the relevance to coping can provide additional insight into the

mechanisms by which S/R influences coping as well as providing developmental

considerations.

Gaps in the Literature

Gaps in the literature of the available research included inconsistent definitions,

lack of connection of use of S/R practices to outcomes, lack of data from adolescents

themselves, and limited generalizability. In two studies, prayer and spiritual healing were

explored but not defined (Sibinga et al., 2006; Yoon & Black, 2006). Praying and hoping

were combined as an active coping strategy with no definition of terms, whether as

separate concepts or as a combined concept (Anie et al., 2002). Lack of definitions and

combining concepts may impede the understanding of how each is relevant to coping

with SCD. Lack of definitions for S/R strategies when describing parental use of

alternative therapies may impede understanding concepts and any existing correlations

between the use of S/R strategies and coping with SCD.

A description of how current S/R practices helped was not identified. The desire of parents and guardians to discuss S/R practices with their health providers was not addressed. Including adolescents' and children's' opinions on preferences for S/R strategies as types of alternative therapies were not provided, but may complement parental reports and guide further inquiry (Sibinga et al., 2006; Yoon & Black, 2006). Documentation of pain experiences to include a complete pain assessment, with consideration of religious and spiritual strategies, may provide valuable information. Examining how religious and spiritual practices affect outcomes such as pain severity and SCD pain crisis was not specifically investigated in the adolescent population.

Researchers for one study noted completing an assessment of the psychometric properties for the RCOPE that was used with the adult population (Bediako et al., 2011). Reliability and validity of the RCOPE or FACIT-Sp in adolescents was not described in a mixed method study (Cotton et al., 2009). To the knowledge of this researcher, the psychometric properties of the RCOPE for use in adolescents with SCD have not been evaluated. The psychometric properties for use of the FACIT-Sp in adolescents under 18 years of age have not been established.

Use of alternative therapies was significant and caregivers considered the topic important to be discussed. Participants indicated that adolescents and children using two or more pain medications were more likely to use religious and spiritual alternative therapies, but there was no indication of the use of pain assessments by caregivers and timing of alternative therapies (Yoon & Black, 2006). The use of S/R coping strategies was common among parents of adolescents and children with SCD (Anie et al., 2002;

Sibinga et al., 2006; Yoon & Black, 2006). One study assessed the parent and child responses (Anie et al., 2002). Only one study examined S/R coping strategies specifically among adolescents (Cotton et al., 2009). Two studies sought the parents' perspectives alone as opposed to the children's/adolescents' and parents' perspectives collectively (Sibinga et al., 2006; Yoon & Black, 2006). Generalization of the use of therapies among caregivers is limited as convenience samples were used (Sibinga et al., 2006; Yoon & Black, 2006).

Data from adolescents or children with SCD were not always obtained, which limits how this research may be translated into practice (Sibinga et al., 2006; Yoon & Black, 2006). Understanding why adolescents reported higher levels of negative religious coping than parents/guardians may likely assist caregivers and pediatric providers in supporting adolescents. Research addressing the adolescent population living with SCD specifically and obtaining their perspectives is warranted. Finally, the studies reviewed used convenience sampling, which limits generalizability. There were no longitudinal studies identified making it complicated to evaluate the influence of spirituality and religiosity using a developmental context. In addition, the ability to observe relational influence of spirituality and religiosity for adolescents over time is not possible with cross-sectional studies.

While the findings from research completed with adults may have bearing on the adolescent population, broad generalizations cannot be made. Combining child and adolescent populations may generate findings that are confounding. The cognitive differences between the two populations may contribute to varied understanding of concepts presented.

Implications and Conclusions

For health care providers, it is vital to be aware of the individuality of adolescents and to include their opinions and values. S/R coping may include bible study, prayer, church attendance, spiritual healing, and other strategies. In order to identify S/R coping preferences, a spiritual assessment is warranted. Completing a spiritual assessment in the clinic or hospital setting may provide the provider with insight on S/R preferences and any areas of concern or distress experienced, particularly in persons living with a chronic illness. Disease severity and pain were related to greater use of S/R coping strategies in the pediatric and adult population. Adolescents living with a chronic illness and/or chronic pain should receive a spiritual assessment more often, as changes in their health status may result in changes to their S/R coping strategies. This review revealed that adolescents are willing to provide information regarding their S/R preferences when acknowledged. Health care providers should be prepared to discuss S/R coping strategies with adolescents and their families.

It is imperative to gain an understanding of adolescents' perspectives rather than just the parents' alone. When comparing spiritual preferences, the responses of adolescents may differ from their parents' perceptions (Cotton et al., 2009). Follow up on the concerns and desires of parents and allowing time for discussion with providers is vital. Individuals may be referred as needed to practitioners such as a chaplain, psychologist, or social worker who can address their S/R concerns. Providers may also consider consulting with other practitioners skilled in providing spiritual care. Adolescents or their families may also be encouraged to contact their personal spiritual care provider, such as a pastor, rabbi, or other religious leader. Permission should be

obtained from the family in the event that medical information is shared with the spiritual provider in order to provide personalized and supportive spiritual care. Including S/R in the care provided allows for an appropriate assessment and communicates that the provider acknowledges and respects their beliefs.

By exploring S/R in the context of living with SCD, the information gained will inform providers of potential resources and spiritual strengths that individuals may draw from and use to cope with their illness. Understanding the influence of S/R on illness and health across the lifespan will assist in individualizing care from a developmentally appropriate and holistic perspective. This understanding will influence the providers' role of considering S/R coping strategies when evaluating health care utilization practices. Providers can assist in managing unique spiritual concerns and develop interventions to address spiritual needs. This involvement is a step towards promoting effective coping to ameliorate symptoms of SCD and improve QOL. Addressing inequalities in care is initiated when providers explore factors unique for each patient and concepts that are significant for the population to incorporate into the plan of care.

In persons with SCD, S/R is worth exploring. Limited research with adolescents identifies S/R as significant concepts that promote healthy outcomes. Developing research studies to further investigate the influence of S/R for adolescents is critical to understanding the concept from a developmental perspective. Additional research exploring religious and spiritual coping strategies as modulating factors for pain experiences in adolescents with SCD is warranted. In addition, this knowledge may assist providers in individualizing spiritual care across the lifespan and incorporating this framework into the practice setting.

As noted in the study completed with adolescents alone (Cotton et al., 2009), adolescents indicated experiencing more negative religious coping than their parents. Evaluating the spirituality and religiosity of adolescents can offer information specific to their life experiences. Spiritual and religious beliefs of parents have influence on their children, but during adolescence a number of changes take place. Adolescents seek to establish their sense of identity, and during these developmental transitions, their spiritual and religious preferences may or may not resemble the spiritual and religious preferences of their parents.

Continuing this research within the adolescent population will inform researchers and allow for specific needs to be addressed in the health care environment. Further exploring the association of spirituality and religiosity to pain severity, coping styles, and health care utilization will provide direction for future research. Addressing differences between adolescent and adult populations may assist providers in refining interventions to avoid hospital readmissions and impact the readmission rate across the lifespan.

Quality of life (QOL) was studied in one study for adolescents (Cotton et al., 2009) and two studies for adults, with findings supporting the relationship between spirituality and their perception of QOL (Adegbola, 2011; Mann-Jiles & Morris, 2009). The studies conducted with adults used two different QOL instruments. One researcher discussed the Quality of Life Scale (QOLS) as an instrument constructed in consideration of diversity (Mann-Jiles & Morris, 2009). For the study conducted with adolescents, there was a relationship between spirituality and school performance (Cotton et al., 2009). School performance is one item used to assess health related quality of life (HRQOL) in the younger population. School functioning, which includes relationships

with peers, is significant for adolescents. Variables perceived to enhance QOL for adolescents might exhibit some similarities as well as differences when compared to adults. Examining the relationship between QOL variables with spirituality and religiosity in adolescents is warranted in order to provide care that is developmentally appropriate.

References

Adegbola, M. (2011). Spirituality, self-efficacy, and quality of life among adults with sickle cell disease. *Southern Online Journal of Nursing Research, 11*(1), 1-16.

Anie, K. A., Stepsoe, A., Ball, S., Dick, M., & Smalling, B. M. (2002). Coping and health service utilisation in a UK study of paediatric sickle cell pain. *Archives of Disease in Childhood, 86*(5), 325-329. doi: http://dx.doi.org/10.1136/adc.86.5.325

Bediako, S. M., Lattimer, L., Haywood, C., Jr., Ratanawongsa, N., Lanzkron, S., & Beach, M. C. (2011). Religious coping and hospital admissions among adults with sickle cell disease. *Journal of Behavioral Medicine, 34*(2), 120-127. doi: http://dx.doi.org/10.1007/s10865-010-9290-8

Benson, P. L., Roehlkepartain, E. C., & Rude, S. P. (2003). Spiritual development in childhood and adolescence: Toward a field of inquiry. *Applied Developmental Science, 7*(3), 204-212. doi: http://dx.doi.org/10.1207/S1532480XADS0703_12

Cohen, S., Kessler, R. C., Gordon, U. L. (1995). Strategies for measuring stress in studies of psychiatric and physical disorder. In S. Cohen, R. C. Kessler, and U. L. Gordon (Eds.), *Measuring Stress: A Guide for Health and Social Scientists* (pp. 3-26)*. New York, NY: Oxford University Press.

Cooper-Effa, M., Blount, W., Kaslow, N., Rothenberg, R., & Eckman, J. (2001). Role of spirituality in patients with sickle cell disease. *Journal of the American Board of Family Practice, 14*(2)*, 116-122.

Cotton, S., Grossoehme, D., & McGrady, M. E. (2012). Religious coping and the use of prayer in children with sickle cell disease. *Pediatric Blood & Cancer, 58*(2), 244-249. doi: http://dx.doi.org/10.1002/pbc.23038

Cotton, S., Grossoehme, D., Rosenthal, S. L., McGrath, M. E., Roberts, Y. H., Hines, J., Tsevat, J. (2009). Religious/Spiritual coping in adolescents with sickle cell disease: A pilot study. *Journal of Pediatric Hematology Oncology, 31*(5), 313-318. doi. http://dx.doi.org/10.1097/mph.0b013e31819e40e3

Dedert, E. A., Studts, J. L., Weissbecker, I., Salmon, P. G., Banis, P. L., & Sephton, S. E. (2004). Religiosity may help preserve the cortisol rhythm in women with stress related illness. *International Journal of Psychiatry in Medicine, 34*(1), 61-77. doi: http://dx.doi.org/10.2190/2y72-6h80-bw93-u0t6

Elixhauser, A., & Steiner, C. (2013). *Readmissions to U.S. hospitals by diagnosis, 2010* (Statistical brief #153). Retrieved from: http://www.hcup-us.ahrq.gov/reports/statbriefs/sb153.pdf

Harrison, M. O., Edwards, C. L., Koenig, H. G., Bosworth, H. B., Decastro, L. & Wood, M. (2005). Religiosity/Spirituality and pain in patients with sickle cell disease. *The Chicago Journal of Nervous & Mental Disease, 193*(4), 250-257. doi: http://dx.doi.org/10.1097/01.nmd.0000158375.73779.50

Ignatavicus, D. D., & Workman, M. L. (2006). *Medical-surgical nursing: Critical thinking for collaborative care.* St. Louis, MI: Elsevier.

Ironson, G., Solomon, G. F., Balbin, E. G., O'Cleirigh, C., George, A., Kumar, M., Woods, T. (2002). The Ironson-Woods spirituality/religiousness index is associated with long survival, health behaviors, less distress, and low cortisol in people with HIV/AIDS. *Annals of Behavioral Medicine, 24*(1), 34-48. doi: http://dx.doi.org/10.1207/s15324796abm2401_05

Kauf, T. L., Coates, T. D., Huazhi, L., Mody-Patel, N., & Hartzema, A. G. (2009). The costs of health care for children and adults with sickle cell disease. *American Journal of Hematology, 84*(6), 323-327. doi: http://dx.doi.org/10.1002/ajh.21408

King, D. E., Mainous, A. G., & Pearson, W. S. (2002). C - reactive protein, diabetes, and attendance at religious services. *Diabetes Care, 25*(7), 1172-1176. doi: http://dx.doi.org/10.2337/diacare.25.7.1172

Koenig, H. G., & Cohen, H. J. (2002). Psychosocial factors, immunity, and wound healing. In H. G. Koenig, & H. J. Cohen (Eds.), *The link between religion and health: Psychoneuroimmunology and the faith factor.* New York, NY: Oxford.

Larson, D. B., Swyers, J. P. & McCullough, M. E. (1998). *Scientific research on spirituality and health: A consensus report*. Rockville, MD: National Institute.

Lerner, R. M., Alberts, A. E., Anderson, P. M., & Dowling, E. M. (2006). In E. C. Roehlkepartain, P. Ebstyne-King, L. Wagener, L., & P. L. Benson (Eds.), *The handbook of spiritual development in childhood and adolescence* (pp.60-72). Thousand Oaks, CA: Sage Publications.

Lynn, C. D., Paris, J., Frye, C. A., & Schell, L. M. (2010). Salivary alpha-amylase and cortisol among pentecostals on a worship and nonworship day. *American Journal of Human Biology, 22*(6), 819-822.
doi: http://dx.doi.org/10.1080/2153599x.2011.639659

Mahoney, A., Pendleton, S., & Ihrke, S. (2006). Religious coping by children and adolescents: Unexplored territory in the realm of spiritual development. In E. C. Roehlkepartain, P.E. King, L. Wagener, & P. L. Benson, (Eds.), *The handbook of spiritual development in childhood and adolescence*. Thousand Oaks, CA: Sage.

Mann-Jiles, V., & Morris, D. L. (2009). Quality of life of adult patients with sickle cell disease. *Journal of the American Academy of Nurse Practitioners, 21*(6), 340-349.
doi: http://dx.doi.org/10.1111/j.1745-7599.2009.00416.x

Matthews, K. A., Salomon, K., Brady, S. S., & Allen, M. T. (2003). Cardiovascular reactivity to stress predicts future blood pressure in adolescence. *Psychosomatic Medicine, 65*(3), 410-415.
doi: http://dx.doi.org/10.1097/01.psy.0000057612.94797.5f

Mihaljević, S., Vuksan-Ćusa, B., Marcinko, D., Koić, E., Kusević, Z., & Jakovljević, M. (2011). Spiritual well-being, cortisol, and suicidality in Croatian war veterans suffering from PTSD. *Journal of Religion and Health, 50*(2), 464-473.
doi: http://dx.doi.org/10.1007/s10943-010-9383-2

National Institute of Health (2012, August). *Genetics home reference: Your guide to understanding genetic conditions, sickle cell disease.* Retrieved from http://ghr.nlm.nih.gov/condition/sickle-cell-disease

Nonnemaker, J. M., McNeely, C. A., & Blum, R. W. (2003). Public and private domains of religiosity and adolescent health risk behaviors: Evidence from the national longitudinal study of adolescent health. *Social Science & Medicine, 57*(11), 2049-2054.
doi: http://dx.doi.org/10.1016/s0277-9536(03)00096-0

O'Connell-Edwards, C. F., Edwards, C. L., Pearce, M., Waccholtz, A. B., Wood, M., Muhammad, M., Y., Whitfield, K.E., Merritt, M., Wellington, C., Byrd, G., McNeil, J.C., Edmonds, H., & Robinson, E. (2009). Religious coping and pain associated with sickle cell disease: Exploration of a non-linear model. *Journal of*

African American Studies, 13, 1-13.
doi: http://dx.doi.org/10.1007/s12111-008-9063-4

Pargament, K. I. (1997). *The psychology of religion and coping*: *Theory, research, practice.* New York, NY: The Guilford Press.

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical, and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology, 9*(6), 713-730.
doi: http://dx.doi.org/10.1177/1359105304045366

Pinckney, R. B., & Stuart, G. W. (2004). Adjustment difficulties of adolescents with sickle cell disease. *Journal of Child and Adolescent Psychiatric Nursing, 17*(1), 5-12.
doi: http://dx.doi.org/10.1111/j.1744-6171.2004.00005.x

Rees, D. C., Williams, T. N. & Gladwin, M. T. (2010). Sickle-cell disease. *Lancet,* 376 (*9757*), 2018-2031.

Sandberg, S., Paton, J. Y., Ahola, S., McCann, D. C., McGuinnes, D., Hilary, C. R., Oja, H. (2000). The role of acute and chronic stress in asthma attacks in children. *Lancet, 356*(9234), 982–987.
doi: http://dx.doi.org/10.1016/s0140-6736(00)02715-x

Schaefer, J. (2010). *Theology 6995 Independent Study in Adolescent Spirituality and Religiosity,* Personal discussion with Jame Schaefer, PhD, Director, Marquette University, Milwaukee, Wisconsin.

Sibinga, E. M., Shindell, D. L., Casella, J. F., Duggan, A. K. & Wilson, M. H. (2006). Pediatric patients with sickle cell disease: Use of complementary and alternative therapies. *Journal of Alternative and Complementary Medicine, 12*(3), 291-298.
doi: http://dx.doi.org/10.1089/acm.2006.12.291

Steiner, C. A., & Miller, J. L. (2006). *Sickle cell disease patients in U.S. hospitals, 2004* (Statistical brief #21). Retrieved from: http://www.hcup-us.ahrq.gov/reports/statbriefs/sb21.pdf

Tartaro, J., Luecken, L. J., & Gunn, H. E. (2005). Exploring heart and soul: Effects of religiosity/spirituality and gender on blood pressure and cortisol stress responses. *Journal of Health Psychology, 10*(6), 753-766. doi: http://dx.doi.org/10.1177/1359105305057311

Weinblatt, M. E. (1998). Sickle cell disease. In S. B. Friedmann, M. Fisher, S. K. Schonberg, & E. M. Alderman (Eds.), *Comprehensive adolescent health care*. St. Louis: Mosby.

Wulff, D. (1997). *The psychology of religion: Classic and contemporary views.* New York: Wiley.

Yoon, S. L., & Black, S. (2006). Comprehensive, integrative management of pain for patients with sickle-cell disease. *The Journal of Alternative and Complementary Medicine, 12*(10), 995-1001. doi: http://dx.doi.org/10.1089/acm.2006.12.995

How Adolescents with Sickle Cell Disease

Describe and Experience Spirituality and Religiosity

Dora Clayton-Jones PhD(c)[1]

Kristin Haglund PhD[2]

Ruth Ann Belknap PhD[3]

Jame Schaefer PhD[4]

Manuscript submitted May 2014 for publication in Journal of Nursing Scholarship

[1]Corresponding Author; Marquette University, College of Nursing, P.O. Box 1881,

Milwaukee, WI 53201-1881; dora.jones@mu.edu; phone 414-219-9080

[2]Marquette University, College of Nursing, P.O. Box 1881, Milwaukee, WI 53201-1881;

kristin.haglund@mu.edu

[3]Marquette University, College of Nursing, P.O. Box 1881, Milwaukee, WI 53201-1881;

ruth.belknap@mu.edu

[4]Marquette University, Department of Theology, Coughlin Hall, Milwaukee, WI 53201-

1881; jame.schaefer@mu.edu

**How Adolescents with Sickle Cell Disease
Describe and Experience Spirituality and Religiosity**

Abstract

Purpose: This study purports to address paucity in the literature regarding how adolescents with sickle cell disease (SCD) describe and experience spirituality and religiosity.

Methods: This was a qualitative descriptive study. Two semi-structured interviews (n=9) were completed for each participant. Data were analyzed using a template analysis style and a concurrent analysis process of data reduction, data display, and conclusion drawing/verification.

Findings: Four main themes emerged to include: (1) spirituality and religiosity as coping mechanisms, (2) shaping of identity, (3) the influence of beliefs on health and illness, and (4) the expectations for health care providers.

Conclusions: Adolescents may seek meaning in their health and illness experiences. Interactions with the health care team can impact the meaning adolescents ascribe to their experiences and nurture their spiritual development.

Clinical relevance statement: SCD is the most common genetic disorder in the U.S. and millions are affected globally (U.S. National Library of Medicine, 2014).

Key Words: Spirituality, religiosity, pediatric, adolescents, sickle cell disease

Introduction

Sickle cell disease (SCD) is a chronic inherited blood disease that shortens life expectancy. Approximately 70,000 to 100,000 Americans have SCD. An estimated 113,098 hospitalizations and over one billion dollars in hospital costs are attributed to SCD annually in the United States (Steiner & Miller, 2006; Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). The hospital 30-day readmission rate for SCD is 31.9% in the United States and accounts for the highest readmission rate compared to all other diagnoses including heart failure or renal failure (Elixhauser & Steiner, 2013). SCD is a debilitating disease that affects many systems including cardiovascular, respiratory, digestive, lymphatic, endocrine, reproductive, urinary, integumentary, musculoskeletal, and the central nervous system (Pinckney & Stuart, 2004; Rees, Williams, & Gladwin, 2010; Weinblatt, 1998). Children and adolescents with SCD experience symptoms, treatments, and complications of their condition that require ongoing comprehensive care. Symptoms and complications include pain, chronic anemia, disability, organ damage, increased risk for infection, and early death (Ignatavicus & Workman, 2006). Frequent hospitalizations are common for many adolescents living with SCD.

SCD is a serious, multisystem disease, for which there is no widely available cure (Claster & Vichinsky, 2003). Adolescents with SCD experience several medical challenges. This includes painful episodes called crises, that can last anywhere from several hours to many days for each occurrence. Adolescents living with SCD face unique psychosocial challenges that interrupt the routines of school and social activities, impact their relationships, and present them with a number of fears and anxieties (Saris, Michaud, & Viner, 2004; Newland, 2008). Medical and supportive management of

adolescents with SCD are critical components of their comprehensive care. Medical supervision includes management of acute and chronic pain, prevention and treatment of infections, and prevention of complications (Rees, Williams, & Gladwin, 2010; Weinblat, 1998). Assessing the needs of adolescents and providing necessary resources and psychosocial support is critical.

SCD impacts adolescents' physical and psychosocial well-being. This can severely impact their ability to experience a high quality of life. People living with a chronic disease such as SCD may seek ways to cope with their disease. The adolescents' ability to cope can positively impact their quality of life (Howard, Thomas, Rawle, Cartwright, & Westerdale, 2008). Spirituality and religiosity (S/R) are elements of humanity that individuals often draw from to cope with life challenges and may be beneficial for persons with SCD (Mahoney, Pendleton & Ihrke, 2006; Pargament, Koenig, Tarakeshwar & Hahn, 2004). Spirituality is the intrinsic capacity of human persons to transcend themselves to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003). Sacred refers to a divine being, ultimate reality, or ultimate truth as perceived by the person (Larson, Sawyers, & McCullough, 1998). *Religiosity* refers to as a commitment to an organized way of knowing and orienting one's self to the religious community's subject of worship (Schaefer, 2010).

Spirituality and religiosity have been shown to help adolescents cope when living with chronic illnesses (Cotton et al., 2009; Haase & Phillips, 2004; Pendleton, Cavali, Pargament, & Nasr, 2002; Snethen, Broome, Kelber, & Warady, 2004; Woodgate &

Degner, 2003). Spirituality and religiosity may influence the experiences of persons living with SCD through coping mechanisms. Coping can provide psychological benefits in response to perceived stressors. Another mechanism by which S/R may influence the experience of SCD, is through physiological health dynamics. Psychoneuroimmunology (PNI) is a dynamic mechanism through which emotional stressors and nervous system activities exert physiological effects on the body and influence or change the course of a chronic illness (Koenig, & Cohen, 2002; Nassau, Tien, & Fritz, 2008).

Based on the psychoneuroimmunology, perceived stressors can have a negative effect on health outcomes and the course of disease (Lutgendorf and Costanzo, 2003). Results of previous research inform us that effective coping can improve the physiological status of adults (Berntson, Norman, Hawkley, & Cacioppo, 2008; Enstrom & Breslow, 2008; Koenig, George, Titus, & Meador, 2004). The influence of S/R on the coping process and physiological status among adolescents has been less frequently examined. It is probable that S/R can assist adolescents in coping with the physical and psychosocial challenges of SCD, but little is known about how teens experience S/R. The purpose of this study is to explore how adolescents with SCD describe and experience S/R. In addition, examining the role of spirituality and religiosity in shaping beliefs about health and illness for adolescents with SCD will also be explored.

Spirituality and Religiosity in Adolescents with Sickle Cell Disease

In conducting a comprehensive review of the literature, five studies addressing spiritual and religious practices were identified in the routines of children and adolescents with SCD or their caregivers. Examples of spiritual and religious practices include prayer, spiritual healing by others, asking for love and forgiveness, and seeking God's

love and care. Spirituality and religiosity were identified as supportive in managing

chronic illnesses and impacting health care utilization for children and adolescents with

SCD (Anie et al., 2002; Cotton, Grossoehme, & McGrady, 2012; Cotton et al., 2009;

Sibinga, et al., 2006; Yoon & Black, 2006). Two studies were carried out with children

under age 13 (Sibinga et al. 2006; Cotton et al., 2012). Two studies sought the opinions

of parents alone (Sibinga et al. 2006; Yoon & Black, 2006) and two studies included

children and adolescents (Anie et al., 2002). Only one study focused on exploring the

perceptions of adolescents (Cotton et al., 2009).

Spiritual and religious practices may be used by caregivers of the children or by

the children themselves to cope. Two research articles discussed spiritual and religious

practices used by parents of children and adolescents with SCD as an approach to coping

and to enhancing clinical care (Sibinga, Shindell, Casella, Duggan, & Wilson., 2006;

Yoon & Black, 2006). Prayer and spiritual healing were identified as spiritual and

religious strategies used most often by parents or guardians of children with SCD (Anie

et al., 2002; Cotton et al., 2009; Cotton et al., 2012; Sibinga, et al., 2006; Yoon & Black,

2006). Spiritual and religious practices were significant for caregivers who used them

with their children with SCD (Sibinga et al., 2006; Yoon & Black, 2006). Researchers

assessed the frequency of the reliance on alternative therapies by parents. Prayer and

spiritual healing were used frequently. The purpose of this study was to examine how

adolescents with SCD describe and experience spirituality and religiosity.

Conceptual Framework

The Spiritual Development Framework developed by Benson & Roehlkepartain

(2008) provided a foundation for conceptualizing the spiritual element of human

development (Figure 1). The framework was chosen for the current study as it provided an approach to understanding the process of spiritual development along with the consideration of involved dynamics. The framework was designed recognizing that spiritual development can contribute to the health and well-being of others or contribute to their detriment. Consideration of spiritual development in the context of health and illness will identify methods to improve the well-being of adolescents. According to the framework three central developmental processes support spiritual development. The processes are (a) Awareness or Awakening, (b) Interconnecting or Belonging, and (c) A Way of Living (Figure 1) (Benson & Roehlkepartain, 2008). Each process is embedded in, and interacts with, other facets of development (d) physical, cognitive, social, emotional, and moral, as well as (e) social context, (f) culture, (g) meta-narratives, and (h) change (time/ growth/ life experiences) (Benson & Roehlkepartain, 2008). The processes lead to outcomes which may be harmful or healthy. Outcomes may be physical, cognitive, affective, or social. The processes may be experienced independently and in various orders. The first, *Awareness or Awakening* is the act of being aware of one's self, others, and the universe in ways that nurture and develop meaning and a sense of identity (Benson & Roehlkepartain, 2008). *Interconnecting or Belonging* is the process of experiencing significance in life events and relationships with others, the natural world, and a divine or transcendent force (Benson & Roehlkepartain, 2008). The process of *A Way of Living* is the expression of one's identity through action and relationships with self, others, the universe, and the sacred (Benson & Roehlkepartain, 2008).

Methods

Research Design

A qualitative descriptive design was used (Sandelowski, 2000). Data were collected from a purposive convenience sample of nine adolescents through individual, semi-structured interviews.

Participants

Participants were recruited from a Midwestern Comprehensive Sickle Cell Center in the United States after receiving Institutional Review Board approval. A convenience sampling approach was used. An announcement was posted within the sickle cell clinic of a large children's hospital. Participants were recruited over 15 months. A total of 11 participants were recruited, although only 9 participated. One participant decided not to participate in the research study and withdrew. One participant completed the demographic form but was not able to schedule interviews. Parental consent and adolescent assent were obtained for adolescents under the age of eighteen prior to participation in the study. Assent was obtained for participants aged 15 to 17 years.

Data Collection

Nine participants (ages 15-18 years) completed a Participant Demographic Survey and participated in two semi-structured interviews. Participant demographic information included: Age, ethnicity, gender, year in school, work status, hemoglobinopathy (SCD type), disease severity, health history, religious affiliation, and denomination. Eight parents were consented and completed a Parent Demographic Survey. Parent

demographic information included: Age, ethnicity, number of children, ages of children, relationship to participant, number of children with SCD, parent with SCD, parent denomination, parent's religious affiliation, frequency of church attendance, level of education completed, marital status, and work status. The Participant and Parent Demographic Surveys were used to describe the participants and their parents.

Data were collected during two semi-structured interviews. Interviews with participants were conducted by the principal investigator (PI) in a private room within the hospital or support group organization. Each interview lasted approximately 50 to 60 minutes. Interview questions were initially written by the (PI). The questions were reviewed by expert qualitative researchers with experience in pediatric and psychiatric nursing, a parish nurse, a social worker, and a minister. Two adolescents served as content reviewers and evaluated the interview questions for understanding, clarity, and that the questions worked as intended. The guide was also reviewed by Dr. Harold Koenig who is a researcher with expertise in religion, spirituality, and health. Revisions were made to the interview guide as indicated by the reviewers prior to conducting interviews with the participants.

Two interview guides were developed specifically for use in conducting the semi-structured interviews. One guide was used with participants who indicated that they had religious beliefs and a second guide was used for participants who indicated that they did not have religious beliefs. Each guide consisted of twenty-four open-ended main questions accompanied by additional probes. The questions in the interview guide were divided into three primary fields of inquiry which include: (a) general information about the participant, (b) spiritual and religious beliefs, and (c) how the participant's spiritual

and religious beliefs influenced their life and health. The guide used for those who indicated not having religious beliefs, was focused more on spirituality and general beliefs. Participants received a $25 compensation after each interview. Interviews were digitally recorded and transcribed by a professional transcriptionist.

The PI developed a field note guide for use during data collection. The guide consisted of three sections to include a) observation notes, b) methodological notes, and c) theoretical notes (Denzin & Lincoln, 1998). Observation notes consisted of details of what the PI saw and heard before, during, and after the interviews. Methodological notes consisted of messages the PI created regarding how to collect the data. Examples of methodological notes included who to contact, when to contact, what to wear, and changes made during the process. Theoretical notes consisted of the PI's thoughts, hypotheses, and critiques. The critiques were of the PI's actions, thoughts, and observations. Theoretical notes assisted the PI in remaining open and receptive to alternative interpretations.

Data Analysis

Descriptive analysis of demographic data were conducted to generate summary information for each participant to provide a general description. Data analysis consisted of using template analysis style (Miller and Crabtree, 1992) and the use of three phases to include data reduction, data display, and conclusion drawing and verification (Miles & Huberman, 1994). Template analysis involves the use of a template as a guide during analysis. The intent is to apply the template to the interview data and using the template to categorize meaningful words and phrases. Modifications were made to the template after each analysis activity.

The Spiritual Development Framework was used to design a template for analysis focusing on three core developmental processes. Data reduction was continuous throughout the analysis process. The PI analyzed all transcripts after each interview. The PI listened to the digital recordings and verified the transcripts in order to make corrections as needed and gained a gestalt of the interviews. The entire interview transcript and field notes for each participant were entered into NVivo 10 for analysis.

An initial coding scheme was developed to code each transcript. The initial coding scheme included the three core developmental processes of spiritual development, to include 1) Awareness, 2) Interconnecting, and 3) A Way of Living (Benson, 2008). Additional codes were added as they developed from the data. After coding the first interview 14 codes were developed. Another researcher independently coded two transcripts with the coding list. Upon comparison of the coding of the PI and the researcher, approximately 80% of the coding matched. This comparison led to a revised list of 23 codes. The PI reviewed the revised list of codes combining codes that were similar in description under one code. Tree nodes were developed for five of the codes. This resulted in a final list of 18 codes.

At the end of each coding session, the PI reviewed codes, checked for redundancy, and combined codes to reduce data describing similar information and reorganized previous codes as needed. A copy of the codes from each session was saved prior to changes made by the PI. As changes were made to the coding scheme, the date and time of the changes were documented in the memo section. Changes were documented in the methodological section of the field notes and used in maintaining an audit trail.

Data were paraphrased and further divided into smaller categories (with codes assigned within and across each category). In NVivo 10 phrases were identified as free nodes initially. As coding progressed, free nodes were reorganized into codes. For some of the codes tree nodes were developed, which represent related or hierarchical categories. Each category was identified with a code and a summary was listed under each code. Using thematic analysis, the PI looked across and within each code for relationships and identified themes. The themes were categorized further into specific phenomena and grouped into specific categories (Munhall, 2001). Codes identified reflected the framework concepts, research questions, interview questions, and identified themes that resulted from analysis of the data.

Rigor

Trustworthiness is significant in qualitative research. Trustworthiness is used to establish and evaluate the worth of a qualitative study (Lincoln & Guba, 1985). As a primary step in contributing to the trustworthiness of the current research, the role of the PI was considered and bracketing was applied. The role of the PI was as an instrument of data collection (Denzin & Lincoln, 2011). The PI is a middle aged African-American female who is an advanced practice nurse working with the pediatric population in a health care organization and in a community health setting. The PI also has experience working in ministries serving children and adolescents. The PI considered personal experiences and views about spirituality/religiosity prior to interviewing participants by acknowledging professional and personal experiences and documenting opinions throughout the data collection process.

Trustworthiness was supported by an iterative review of interview data. In an

effort to ensure trustworthiness a list of strategies will be provided to include credibility,

transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility is

evaluation of whether the research findings represent a credible analysis of the data.

Techniques that will be used to maintain credibility include prolonged engagement,

respondent validation, and triangulation (Lincoln & Guba, 1985; Maxwell, 2005).

Prolonged engagement involves spending enough time to understand the phenomenon of

interest. The PI interviewed participants using a semi-structured approach on two

separate occasions for up to a total of two hours. The time for completing two interviews

per participant and arriving at saturation of data took 16 months. The PI completed

interviews for 9 participants within a 16 month time frame allowing for *prolonged*

engagement of the PI. This prolonged engagement allows time for building trust and

rapport among participants. The interviews were transcribed verbatim and included what

the PI considered to be significant. Notes were documented on observations made during

the interview process.

Respondent validation took place by soliciting feedback and confirmation about

conclusions from participants during the interviews and upon conclusion of the

interviews (Maxwell, 2005). The biases and misunderstandings of the PI were determined

in order to lessen the possibility of misinterpreting the responses of the participants.

Triangulation is used to increase credibility through use of different sources,

methods, investigators, and theories (Lincoln & Guba, 1985). For the current study more

than one source was used by interviewing nine participants. Each participant was

interviewed on two separate days and in some instances during two separate seasons of

the year.

Transferability refers to the researcher providing a thorough description of the research findings (Lincoln & Guba, 1985). The description should allow other researchers to determine if results can be applied to other settings. A summary listing demographic data of all study participants is provided. Comparisons were made between adolescent participants (Maxwell, 2005). Changes take place during development and comparisons are warranted.

Confirmability refers to the extent to which research can be confirmed by others (Lincoln & Guba, 1985). An audit trail was maintained throughout the current study and the analysis. The audit trail consisted of all documentation detailing observations made during data collection, field notes, observation notes, methodological notes, theoretical notes, code descriptions, and themes as well as any revisions or changes to the code descriptions and categorization.

Dependability emphasizes the need for the researcher to take into consideration changes in the context (Lincoln & Guba, 1985). Coding checks were completed between the PI and another researcher using two separate participant transcripts. Use of an inquiry audit, identifying discrepant data, and making comparisons between participants was used to establish confirmability and dependability. The PI used an audit inquiry to include raw data (field notes and digital recordings), data analysis and reduction products (summaries and data matrices), data reconstruction and synthesis products (thematic categories and synthesis), process notes (procedure and design strategies), and materials related to materials and disposition (study proposal).

In addition, the PI identified discrepant data for analysis to support confirmability and dependability (Maxwell, 2005). This is data which the PI was unable to account for

with a specific interpretation. In this case the PI assessed whether to maintain or modify the conclusion. The PI identified all data which did not fit the conclusions made by the PI. Other qualitative researchers were asked to assist the PI in reviewing and evaluating discrepant content allowing conclusions of discrepant data to be made. Discrepant data were reviewed and maintained as not corresponding to conclusions or modified to fit conclusions made by the PI.

Results

Participants

The final sample size was 9 participants ranging in age from 15 to 18 years ($M age = 16.2$). The majority of the sample was African-American (n=8), followed by African-American and Sicilian descent (n=1). All participants attended high school, and three attended a Catholic school. Three of the participants were male and 6 were female. Six participants indicated that their hemoglobinopathy type was sickle cell anemia (HbSS); two hemoglobin S-beta-zero-thalassemia (Hbβ°/S); and one hemoglobin C (HbSC). Participant and parent demographics are presented in Table 2.

Themes

A total of four themes emerged to include: (1) (S/R) as coping mechanisms, (2) shaping of identity, (3) influence of beliefs on perspectives of health and illness, and (4) expectations for health care providers. Theme One, S/R as coping mechanisms, consisted of six threads. Theme Two, expectations of health care providers, consisted of two threads. Each theme will be presented and described along with the threads.

Table 2.

Participant and Parent Demographics

	Participants N = 9		Parents N = 8	
Mean age	16.2 ± .97 yrs (N= 9)		40.5 ± 6.8 yrs (N = 8)	
	N	%	N	%
Gender				
Female	6	67	7	87.5
Male	3	33	1	12.5
Ethnicity				
African	0	0	1	12.5
African-American	8	89	6	75
Sicilian/African American	1	11	1	12.5
Denomination				
Baptist	4	44	3	37.5
Catholic	1	11	1	12.5
Pentecostal	2	22	1	12.5
Presbyterian	1	11	1	12.5
Atheist	1	11	0	0
Non-Denominational	0	0	2	25

Table 2.

Participant and Parent Demographics (continued)

	Participants N = 9		Parents N = 8
Frequency of church attendance			
1-2 times/ week	5		7
3 times/ month	1		0
Once per / month	2		0
Special Occasions	0		1
>1 year	1		0
SCD Type			
HbSS	6	67	
HbSC	2	22	
S β^0 thal	1	11	
Times in hospital past year			
None	1	11	
1	4	44	
2	2	22	
5	1	11	
11	1	11	
Times in hospital over life			
0-10	2	22	
11-25	2	22	

Table 2.

Participant and Parent Demographics (continued)

	Participants N = 9		Parents N = 8
26-50	2	22	
>50	3	33	
Pain crises past year			
1-2	4	44	
4	1	11	
10	1	11	
10-20	1	11	
20+	1	11	
30-36	1	11	
Had operation			
Yes	5	55	
Gall Bladder	4	44	
Lymph Nodes	1	11	
Spleen	1	11	
Tonsils	2	22	
No	4	44	
Yes	7	77	
No	2	22	

Theme One: Spirituality and Religiosity as Coping Mechanisms

Based upon the data, participants expressed using their S/R to cope with the challenges of life and the impact of their SCD.

Thread one: Interconnecting with God. Many participants believed that their relationship with God provided a sense of comfort when facing challenges in life, and in dealing with their sickle cell disease. They described their religiosity as consisting of a personal relationship with God and that they modeled how they lived their lives after Him. They believed that their relationship with God gave them a foundation for life, positioned them to be a better person, and encouraged them to making the world a better place. Participants indicated that their relationship with a Higher Power helped them to put experiences into perspective and that this was especially significant during stressful times. Prayer and the ability to talk to God was noted as the most frequent style of connecting with God and supporting their ability to cope. Prayer was described as an opportunity to release things that were burdensome or difficult. Participants shared that attending religious services, reading the bible, reflecting on religious symbols, participating in religious traditions, and having the opportunity to repent for their sins were additional methods they used to connect with God. Participants indicated that their times of prayer took place when life was going well, and also during stressful periods. Challenging events in their lives included their experiences with their SCD (pain crises, surgeries, blood transfusions), staying current with their assignments at school, and participating in extracurricular activities. Moments of prayer occurred most frequently during episodes of pain crises and illness experiences. A participant commented on her relationship with God and how this influences her coping. She said:

"I feel comfortable enough to pray when I'm really in need, even when like my

best friend….I can't talk to her about it or I don't feel comfortable. So I feel like,

pretty strong in praying and just letting out all of my problems, or whatever is

bothering me or my feelings to Him." (15 y.o. female)

Another participant described his relationship with God to include receiving direction

from Him. He said:

"He's like a father figure that puts everything into place that makes sense, and

comforts you when you need it. He can talk to you and you really, like actually

listen."(16 y.o. male)

Having a relationship with God provided participants with a consistent source of comfort

and strength to rely on when needed. They took time to reflect on their relationship

during stressful periods.

Participants believed that without their connection to God, they would lose hope,

and have a negative outlook on life. There were times when they doubted their faith when

confronted with pain crises, surgeries, or other challenges, but indicated they remained

committed to their belief system. Their S/R provided them with a positive outlook and

gave them the inspiration to persevere in life despite challenges. They held the belief that

God creates ways to cope with challenges and that effort is needed on behalf of the

individual as well. They believed that God was present with them during their most

difficult moments and this was comforting. Some expressed the realization that they do

not have control over everything. They believed that there came a time in life when they

had to make a decision to surrender themselves and the situation to God. They believed

their lives were planned out by God and that there are moments when the situations they

face can only be handled with God. Participants indicated that they gave thanks to God when making it through a pain crisis or other episode of illness because they felt they could not have handled it alone.

      Thread Two: Interconnecting with others. Participants identified family members, friends, spiritual leaders, and other adults (health providers, teachers) as providing religious and spiritual support when facing stressors. Family was mentioned often with regards to providing a spiritual foundation and spiritual support during difficult times. Family members consisted of parents, siblings, aunts, uncles, cousins, and grandparents. Participants mentioned that there were times when their parents assumed a role of spiritual authority by praying and providing words of encouragement when facing pain crisis/illness. Participants also reflected on their grandmother or a "grandmother figure" periodically sharing words of wisdom and how they reflected on these moments during pain crises/illnesses. Participants relied on immediate and extended family members for having conversations/listening, providing prayer, giving advice, gathering together for events/dinner, and preparing their favorite foods.

      Participants looked forward to calls and visits from their friends while they were in the hospital, and felt this helped them cope with being in the hospital. Technology was viewed as being helpful in maintaining communication with friends while hospitalized. Most indicated having had at least one or two very close friends. Friends were of diverse ethnic and religious backgrounds, and participants verbalized that they developed a mutual respect for one another. Friends provided insight by bringing practical balance as it relates to their faith, realistically balancing the expectations of religious traditions with their health needs/schedules. Participants described experiencing a level of connectedness

with others through volunteering and using their SCD experiences to help others. As they advocated for others, this assisted them in coping with their SCD. Friends were described as being supportive by sharing interests/goals, having fun/laughing, talking/providing advice, participating in activities (sports, movies, games, shopping, dining, etc.), visiting each other's church, and being creative together.

Participants mentioned that their pastor/spiritual leader visited them when hospitalized and indicated that their attentiveness and support was memorable and appreciated. Health providers and teachers were also mentioned as making a connection with participants, and at times providing spiritual support. Having a caring attitude and a sense of humor were mentioned as qualities appreciated in pastors/spiritual leaders as well as other adults in their lives.

Thread Three: Interconnecting with creative arts/activities. In addition to connecting with God, family, and friends, participants also described their connections with the creative arts and other activities that provided meaning in their lives. Through art, playing an instrument, singing, dancing, acting, and writing, participants described experiencing a level of connectedness that allowed them to express themselves and provided a sense a relief from the stressors they faced. They also communicated feeling a sense of connectedness at times with nature and would take the time to go for walks or pause and reflect on the natural world.

Thread Four: Scriptural meta-narratives. Participants believed that the Bible was a reminder to them of how to respond in everyday life and indicated that reflecting on scriptures was part of their routine, more often when in pain or facing challenges. Specific moments were mentioned when certain scriptures stood out from past theology

classes, conversations, or experiences and applied to a current situation. Many believed that there was a scripture that is relevant for any situation. As one participant said when sharing their belief of scriptural text:

"Scriptures get into your psyche, get into your spirit, and come back to you when needed." (16 y.o. male)

They believed that reading scriptures in the Bible is one way to receive words and direction from God. Phrases from scriptures that were often used as a reference included: "…by His stripes we are healed" and "Fear not, for I am with you…" There were also paraphrases and phrases that were based on scriptural context that participants shared: "He will not put more on you than you can bear," "God is in control," "It's God's will," and "Faith without works is dead." Many shared hearing a specific scripture from a grandparent or other elder figure and that this was meaningful and inspiring. Participants verbalized their appreciation of the wisdom gained from scriptural text and the ability to apply it to their lives.

Thread five: Transcendent experiences. In addition to praying and communicating with God, participants described other moments of transcendence. Some indicated that they would ask God for help to see themselves past a pain crisis. Rather than thinking about the current pain they were experiencing, they sought His help to envision themselves past the pain crisis episode and in the stages of recovery. One participants described her experience about an activity. She said: "I will just think about dancing and it helps me feel better." (16 y.o. female). Besides prayer and dancing, additional activities they used to experience transcendence included playing an instrument, listening to music, or reading. Many expressed belief that God had His hand

in their lives and that no matter what circumstances they faced it was important to focus on remaining in a state of peace.

Theme six: Acceptance and finding meaning. Participants indicated that their S/R encouraged them to focus on what provided meaning in their lives, and provided an outlet for them to express themselves. Acceptance of their diagnosis and the treatment regimen, allowed them to acknowledge the belief that there was a reason for their experiences. Participants believed that everyone has a purpose and that their sickle cell experiences were part of their purpose and meaning in life. This included helping others with sickle cell disease and advocating for improved care. Participants expressed that trials propelled them "to another level and place in life" and assisted in developing perseverance. They found meaning in their sickle cell experiences. One 15y.o. male compared his sickle cell pain crisis to Jesus being beaten and stoned. He said, "If Jesus experienced pain, I can bear this and come out a stronger person." For one participant, writing in a diary was a way to reflect on self, others, and find meaning in experiences. Making plans for the future and volunteering in areas when they could not participate physically were significant and something that gave them hope. Participants indicated that their relationship with God gave them meaning and was an asset in their lives.

Theme Two: Shaping of Identity

Participants indicated that their religiosity shaped their morals. They often used religiosity as a frame of reference during moments of reflection and making decisions. Many indicated that their beliefs kept them looking towards the future and to think about what contributions they would make as an adult. Many held the belief that their lives were planned out by God and that it was important to live their lives accordingly.

Participants mentioned that connecting with God, others, and the creative arts contributed to influencing them as a person. It was also significant to be accepting of others' beliefs and learn more about what they value. Embracing the diversity of peers and others was considered to be critical to their self-awareness and development. They shared that their faith gave them the desire to get along with others in spite of differences, attitudes, or disagreements.

Participants verbalized acceptance of their sickle cell disease and held the belief that there was a reason for the experiences, that everyone has purpose, and that their sickle cell experiences were part of their purpose/meaning in life. They believed that it was important to use their experiences to help others. Participants indicated that their faith caused them to believe that their current state of illness would not always exist, so it's important to think of the future and consistently look forward.

Theme Three: Influence of Beliefs on Health and Illness

Health maintenance was considered to be significant in order to avoid serious outcomes. This included awareness and avoidance of triggers. Taking time to care for the body was a commonly held belief and practice. Participants expressed the importance of being aware of potential threats to health, to avoid illness, and keep staying out of the hospital a constant goal. They also expressed that having knowledgeable is key to optimal health. As one participant described:

> "If I make a visit to the ER, and I am not crying and screaming, my situation is
> not perceived to be as serious as it is, and I am not seen quickly." (16 y.o. female)

This comment suggests that the emergency room provider's perception of the

participant's health status differed from the participant's perception. In the situation previously described, the participant used S/R beliefs to assist her in remaining calm and composed during a vaso-occlusive pain crisis. The participant believed that the health care provider completing the initial assessment appeared to weigh the observational assessment more heavily than the participant's verbal report of pain.

Many considered speaking positively about their lives should be a daily practice. They expressed that a healthy lifestyle follows living according to Godly principles and that unhappy or ill thoughts could affect their health. One 16 y.o. participant shared her thoughts about beliefs and health. She said:

"I think that if you are trying to live upright before God and actually try to keep yourself healthy, then sure. Sure you're going to be healthy and live a good life."

(16 y.o. female)

Some expressed that one's life span could be shortened based on their behavior towards others. They also felt their beliefs and mind could overpower what their body felt and experienced, as well as prepare them for what may happen in the future. Some felt that applying their beliefs and faith to medical opinions, whether negative or positive, would lead to improved physical outcomes. Many believed that focusing on their current illness experience could affect their overall SCD status. Some indicated that it was important to imagine doing what they enjoy when their physical condition would not allow them to participate in the activity.

Faith was described as being significant to rely on during illness. They believed their faith provided hope, gave them strength, instilled peace, and assisted them in overcoming challenges. They believed their faith provided them with the endurance to

avoid frustrations, deal with difficult people, face life challenges, and avoid major stressors on the body. The belief that an inner relationship with God was needed to focus on getting better was a common belief. Participants believed that with God and prayer their physical outcome could improve. It was significant for them to not take their health or their life for granted.

Theme four: Expectations for Health Providers

Participants shared their thoughts about communicating their S/R beliefs to health care providers. Some participants indicated that having health providers assess their S/R would depend on how the questions are prefaced. Some felt that some providers may not approach the question respectfully, making it uncomfortable to answer. Many held the general opinion that if beliefs intersect health and illness, then the information should be included in a general assessment. Some indicated that providers should know the belief/faith system of the patient by observing their actions. As one participant described: "If it appears as if I need quiet time to pray, this should be honored without asking" (16 y.o. female). Some felt completing an assessment of beliefs was not expected, but would be welcomed if part of a general assessment.

Participants indicated that their S/R was generally not assessed or included in care. Participants indicated that spiritual care was provided on limited occasions by health providers (with 4 participants). One participant described the spiritual care provided by a health provider as "refreshing." Participants indicated that they appreciated the following qualities in their health provider: knowing their patient and their preferences, anticipate the patient's needs, being available/present, providing humor, respond to the patient's needs, and respect. There were two threads that emerged as

participants conveyed their requests and include religiosity is personal/private and that sharing S/R beliefs can be risky.

Thread One: Religiosity is private, personal, and communal. Participants described their S/R as personal (meaning a relationship between the individual & God) and private (their relationship with God should not be discussed among others). They also expressed being a member of an organized religious community. For the instances where another person of faith assessed and provided spiritual support, the support was consistently received. Participants often depended on their parents for nurturing their S/R, peers who may or may not have similar beliefs or experiences, and spiritual leaders. Participants mentioned a primary care provider, a hematologist, a nurse, and social workers as providers who encouraged them to rely on their faith and/or provided spiritual support. These were generally instances when the S/R of the participants was known by the provider.

Thread Two: Sharing S/R beliefs is risky. Participants indicated that sharing their beliefs with health providers may be risky. There is the fear of being misinterpreted. Some expressed that the outcome of sharing beliefs could be positive while some believed that sharing S/R beliefs could result in an undesirable experience. They also expressed the concern of conflicting faiths/beliefs between the participant and the provider and this impacting the potential outcome. Some participants expressed the desire for a similar belief system between the provider and the patient to accommodate the inclusion of S/R in their health care. The ability to trust the individual performing the assessment was significant. Concern was expressed about the potential for providers to spread rumors if privy to information regarding S/R beliefs of the participant, or treat the

participant differently (most often observed to be a concern with male participants).
Participants also expressed their desire to be treated fairly once their S/R beliefs are
known. As one participant shared:

"I don't want to scare someone off with the topic of religion." (16 y.o. female)
Participants believed that people in general may not want their religious beliefs
associated with their health, and therefore may be reluctant to share. Sharing information
was generally felt to be okay if the purpose was to accommodate beliefs. Participants
expressed that they did not want their providers to dismiss their physical needs when the
S/R beliefs of the adolescent is known. Adolescents desired to be treated as a whole
person and not one obsessed with religion/beliefs.

Summary

Four major themes were identified: spirituality and religiosity as coping
mechanisms, shaping of identity, the influence of beliefs on health and illness, and the
expectations for health care providers. Spiritual and religious coping mechanisms were
salient among participants with SCD. Participants' spirituality and religiosity often
intersected their beliefs regarding health and illness.

Discussion

The main purpose of this study was to explore how adolescents with SCD
describe and experience S/R. Findings from this study identified ways participants relied
on their S/R to cope with life and specifically their SCD. S/R coping for participants
encompassed interconnecting with God, interconnecting with others, interconnecting with
creative arts, scriptural metanarratives, transcendent experiences, and acceptance and

meaning.

   Participants described using S/R to cope with their SCD and life challenges. Prior studies have reported on how adolescents use S/R to manage illnesses (Haase & Phillips, 2004; Pendelton, Cavali, Pargament, & Nasr, 2002; Snethen, Broome, Kelber & Warady, 2004; Woodgate & Degner, 2003). These findings are not generalizable to all adolescent chronic disease populations. Previous research to include adolescents with SCD explored S/R needs of adolescents as mechanisms of coping rather than as antecedents for coping (Anie et al., 2001; Cotton et al., 2009; Sibinga et al., 2006; Yoon et al., 2006). While research has addressed S/R in this population, the scope and completed research is limited. Prior research focused on children and adolescents combined (Anie et al., 2001; Sibinga et al., 2006; Yoon et al., 2006), and one study concentrated on adolescents in early and middle adolescence (Cotton et al., 2009). Developmental needs change across the lifespan. The current research was conducted when most of the participants were in the middle adolescence stage. This allows for findings to be more generalizable.

   Participants were descriptive in providing information on how their beliefs and experiences shaped their identity. Participants relayed how their experiences influenced who they are today. The current study gave participants an opportunity to reflect and provide in depth information regarding their beliefs. The Spiritual Development Framework used to guide this study, suggests that significant life experiences may influence spiritual development (Benson & Roehkelpartain, 2008). Participants were detailed and expressive in their descriptions for the current study. This may have been attributed to their S/R maturity and/or their life experiences. Participants verbalized how they used their SCD experiences to help others, inform communities, and advocate on

behalf of participants with SCD. This information could be helpful in identifying methods to foster development for participants who experience frequent hospitalizations and often separated from their peers.

Prior research identified S/R as protective factors for participants (Davis, Kerr, & Kurpius, 2003; Hodge, Cardenas, & Montoya 2001; Haglund & Fehring, 2010). Their S/R affected their ability to cope, avoid substance use, and delay sexual activity. In the current study participants participated in a collaborative relationship with God where they believed "I have to do my part." Participants believed that caring for their bodies was significant if they expected God to help them feel better. Taking medications as prescribed, eating healthy most of the time, and treating others with respect were considered important for healthy outcomes. The relationship between negative emotions and negative health outcomes was somewhat surprising. While not explicitly described, participants demonstrated an awareness of the PNI concept as a determinant of health.

Participants considered their relationship with God to be personal. They also felt that their S/R beliefs should not be openly shared with others. While this was a common belief among the participants interviewed, most indicated that assessment of the S/R beliefs would be fine for the purpose of enhancing overall health outcomes. A few participants provided instances where health providers provided S/R care. They indicated being open to receiving S/R care from the providers and stated they were not offended. Prior research conducted with children with asthma revealed that having their S/R addressed was contingent on the acuity of the clinical event (Cotton et al., 2013). The complexity of SCD may cause participants to rely more on their S/R to cope. Participants in the current study welcomed S/R assessment, but indicated that the interaction

presented by the health provider upon assessment can influence their level of responses. In a descriptive mixed-methods design, participants' preferences for primary care provider interactions were examined (Schaeuble, Haglund, and Vukovich, 2010). Participants indicated that having a provider who was able to give consistent care, maintain confidentiality, and convey a caring attitude were behaviors they preferred. Interactions between participants and their health providers may impact the completion of a health assessment and inclusion of pertinent data.

Limitations

The current study explored spirituality and religiosity in participants living with sickle cell disease. One of the participants indicated not having religious beliefs. Information regarding participants' descriptions and experiences of spirituality is therefore limited to a predominantly religious group. Another potential limitation is response bias, if participants answered questions in a manner they felt would please the PI. This would include the possibility that participants withheld information from the PI. Finally, participants receive specialized care at a well-supported sickle cell clinic and their experiences may differ from those who do not receive a similar category of care.

Research and Practice Implications

This study is the first qualitative study to examine how adolescents with SCD describe and experience S/R. Future research studies are needed to better understand the significance of S/R in their lives. Using semi-structured interviews to explore the S/R of adolescents' parents and any influences this may have on adolescents is warranted for the participants in the current study often mentioned their parents as having influence on

their spirituality and religiosity. In addition, exploring positive and negative religious coping in this population along with their parents coping styles can assist in fostering communication between adolescents and parents as well as health providers. Spiritual and religious needs of the family and adolescents can be assessed in order to provide optimal holistic care. Exploring gender differences in how adolescents experience S/R may lend additional insight on developing individualized interventions. Examining global differences in S/R coping mechanisms would allow for comparisons to be made across populations. Health care providers could also be included in future research studies and allow for comparisons to be made between providers and adolescents.

The framework was functional as a guide for developing research questions and completing data analysis. Future pediatric research should explore use and functionality of the framework in guiding research and interpreting data.

Embracing an approach that is patient centered and considerate of the adolescents' S/R beliefs will enhance their holistic outcomes. Having an awareness of adolescents' preferences and beliefs are critical for assessment and integration into the provider's approach to practice. Assessing the concerns of adolescents with SCD throughout their adolescent stages of development can assist health care providers in addressing their fears and needs on an ongoing basis. The S/R beliefs of adolescents can impact the challenges they face and assist them in managing their disease and concerns

In a systematic review of the literature, authors concluded that there were no consistent definitions for spirituality and religiosity (Rew & Wong, 2006). Findings from this study can be used to direct future research and gain a greater understanding of how adolescents use these terms. This information can increase awareness of nurses and

support the integration of S/R into the plan of care.

Future research is needed to gain an enhanced understanding adolescents' beliefs and attitudes regarding heath care providers. This can facilitate improved provider-patient communication, interaction, and relationships. Determining a multidisciplinary approach to meeting the S/R needs of adolescents with SCD may facilitate improved clinical outcomes and patient/family satisfaction. Coping with a chronic illness during adolescence can be a stressful period. This can be alleviated by addressing their spiritual needs and seeking out approaches to improve the patient-provider relationship. Health providers are in an optimal position to integrate S/R into the patient's plan of care. Further exploring S/R in adolescents with SCD can support the knowledge of health providers and the provision of holistic care.

Conclusions

Results from the current study highlight the significance of examining S/R in an age-specific population. Spirituality and religiosity are salient for adolescents with SCD. Participants indicated that they held on to their beliefs and their relationship with God regardless of any challenges they faced. Attending to the spiritual S/R experiences of participants and assisting them in expressing their beliefs in a supportive environment can nurture their development and assist them in coping with their health matters and concerns. Supporting their spirituality has the potential to improve the quality of life not only during adolescence, but also during adulthood. Understanding and meeting their S/R needs can provide adolescents with resources that can enhance their coping and foster resilience. This can lead to a healthier lifestyle. Adolescents may seek meaning in their

health and illness experiences. Interactions with the health care team can impact the

meaning adolescents ascribe to their experiences and nurture their spiritual development.

References

Benson, P. L., & Roehlkepartain, E. C. (2008). Spiritual development: A missing priority in youth development. *New Directions for Youth Development,* 118, 13-28. doi: http://dx.doi.org/10.1002/yd.253

Cotton, S., Grossoehme, D.H., Bignall, W.R. & Weekes-Canu, J.C., 2013. Should my provider pray with me? Perspectives of urban adolescents with asthma on addressing religious and spiritual issues in hypothetical clinical situations. *Journal of Religion and Health*, 53 (*2),* 604-613. doi: http://dx.doi.org/10.1007/s10943-013-9790-2

Cotton, S., Grossoehme, D.H., Rosenthal, S.L., McGrath, M.E., Roberts, Y.H., Hines, J., Yi, M.S. & Tsevat, J. (2009). Religious/Spiritual coping in adolescents with sickle cell disease*. Journal of Pediatric Hematology Oncology, 31* (5), 313-318. doi: http://dx.doi.org/10.1097/mph.0b013e31819e40e3

Denzin, N.K. & Lincoln, Y.S. (1998). Methods of collecting and analyzing empirical materials. In Denzin, N.K. & Lincoln, Y.S. (Eds.). Collecting and interpreting qualitative materials. Thousand Oaks, CA: SAGE.

Haase, J.E. & Phillips, C.R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing, 21*(3), 145-149. doi: http://dx.doi.org/10.1177/1043454204264385

Elixhauser, A. & Steiner, C. (2013). *Readmissions to U.S hospitals by diagnosis, 2010* (Statistical brief #153). Retrieved from http://www.hcup-us.ahrq.gov/reports/statbriefs/sb153.pdf

Haglund, KA., & Fehring, R.J. (2010). The association of religiosity, sexual education, and parental factors with risky sexual behaviors among adolescents and young adults. *Journal of Religion and Health,* 49, 460-472. doi: http://dx.doi.org/10.1007/s10943-009-9267-5

Howard, J., Thomas, V.J., Rawle, H., Cartwright, R. & Westerdale, N., (2008). Quality of life and pain management in sickle-cell disease. *Pediatric Health, 2*(3), 377–391. doi: http://dx.doi.org/10.2217/17455111.2.3.377

Koenig, H.G. & Cohen, H.J. (2002). Psychosocial factors, immunity, and wound healing. In H.G. Koenig, & H.J. Cohen (Eds), *The link between religion and health: Psychoneuroimmunology and the faith factor.* New York, NY: Oxford.

Maxwell, J.A. (2005). *Qualitative research design: An interactive approach (2nd ed.).* Sage: Thousand Oaks, CA.

Miles, M.B. & Huberman, A.M. (1994). Qualitative Data Analysis (2nd edition). Thousand Oaks, CA: Sage Publications.

Miller, W.L., & Crabtree, B.F. (1992). Primary care research: A multimethod typology and qualitative road map. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research*. Newbury Park, CA: Sage.

Munhall, P.L. (2001). *Nursing research* (3rd ed.). Columbia, SC: Jones & Bartlett.

Nassau, J.H., Tien, K., & Fritz, G.K. (2008). Review of the literature: Integrating psychoneuroimmunology into pediatric chronic illness interventions. *Journal of Pediatric Psychology, 33*(2), 195-207. doi: http://dx.doi.org/10.1093/jpepsy/jsm076

Pendleton, S.M., Cavalli, K.S., Kenneth, B.A., Pargament, K.I. & Nasr, S.Z. (2002). Religious/spiritual coping in childhood cystic fibrosis: A qualitative study. *Pediatrics, 109*(1), 1-11. doi: http://dx.doi.org/10.1542/peds.109.1.e8

Rew, L. & Wong, Y.J. (2006). A systematic review of associations among religiosity/spirituality and adolescent health attitudes and behaviors. *Journal of Adolescent Health*, *38*, 433– 442. doi: http://dx.doi.org/10.1016/j.jadohealth.2005.02.004

Sandelowski, M. (2000). Focus on research methods: What ever happened to qualitative description? *Research in Nursing & Health, 23,* 334-340. doi: http://dx.doi.org/10.1002/nur.4770170611

Schaefer, J. (2010). *Theology 6995 Independent Study in Adolescent Spirituality and Religiosity,* Personal discussion with Jame Schaefer, PhD, Director, Marquette University, Milwaukee, Wisconsin.

Schaeuble, Haglund, & Vukovich (2010). Adolescents' preferences for primary care provider interactions. *Journal for Specialists in Pediatric Nursing, 15*(3), 202-210.
doi: http://dx.doi.org/10.1111/j.1744-6155.2010.00232.x

Snethen, J.A., Broome, M.E., Kelber, S., & Warady, B. (2004). Coping strategies utilized by adolescents with end stage renal disease. *Nephrology Nursing Journal, 31*(1), 41-9.

U.S. National Library of Medicine (2014). National Institute of Health. *Genetics home reference: Your guide to understanding genetic conditions, sickle cell disease.* Retrieved February, 10, 2014 from http://ghr.nlm.nih.gov/condition/sickle-cell-disease

Woodgate, R.L. & Degner, L.F. (2003). A substantive theory of keeping the spirit alive: the spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing, 20* (3), 103-119.

doi: http://dx.doi.org/10.1053/jpon.2003.75

BIBLIOGRAPHY

Aday, L. (1994). Health status of vulnerable populations. *Annual Review of Public Health, 15,* 487-509. doi: http://dx.doi.org/10.1146/annurev.publhealth.15.1.487

Adegbola, M.A. (2007). The relationship among spirituality, self-efficacy, and quality of life in adults with sickle cell disease. *University of Texas at Arlington;* PhD (169 p).

Adegbola, M. (2011). Spirituality, self-efficacy, and quality of life among adults with sickle cell disease. *Southern Online Journal of Nursing Research, 11*(1), (19p).

Albaugh, J.A. (2003). Spirituality and life-threatening illness: A phenomenologic study. *Oncology Nursing Forum*, 30, 593–598. doi: http://dx.doi.org/10.1188/03.ONF.593-598

American Academy of Pediatrics Committee on Sports Medicine and Fitness. Medical conditions affecting sports participation (1994). *Pediatrics*, *94*(5), 757-60.

American Nurses Association. Scope and standards of practice. Silver Spring: American Nurses Association. 2010: 23.

American Holistic Nurses Association. Holistic nursing: Scope and standards of practice. Silver Spring: American Holistic Nurses Association, American Nurses Association. 2010:1.

American Nurses Association Code of Ethics for Nurses with Interpretive Statements. http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/Code-of-Ethics.pdf (Last revised, November 15, 2010).

Ameringer, S. & Smith, W. (2011). Emerging biobehavioral factors of fatigue in sickle cell disease. *Journal of Nursing Scholarship, 43*(1), 22-29. doi: http://dx.doi.org/10.1111/j.1547-5069.2010.01376.x

Anderson, J.T., Liu, C., Kryscio, R.J. (2008). Blood pressure response to transcendental meditation: A meta-analysis. *American Journal of Hypertension, 21*(3), 310-316. doi: http://dx.doi.org/10.1038/ajh.2007.65

Anie, K.A., Stepsoe, A., Ball, S., Dick, M. & Smalling, B.M. (2002). Coping and health service utilisation in a UK study of paediatric sickle cell pain. *Archives of Disease in Childhood, 85* (5), 325-329. doi: http://dx.doi.org/10.1136/adc.86.5.325

Astin, A.W., Astin, H.S., Lindholm, J.A., Bryant, A.N., Szelenyi, K., & Calderone, S. (2005). The spiritual life of college students: A national study of college students' search for meaning and purpose. Los Angeles: Higher Education Research Institute, UCLA.

Bachman, J.G., Johnson, L.D., & O'Malley, P.M. (2010). Monitoring the future: Questionnaire responses from the nation's high school seniors. Ann Arbor, MI: Institute for Social Research, 386 pp.

Barbarin, O. (1994). Risk and resilience in adjustment to sickle cell disease: integrating focus groups, case reviews, and quantitative methods. *Journal of Health Social Policy, 5,* 97-121. doi: http://dx.doi.org/10.1300/J045v05n03_07

Barden, E. M., Zemel, B. S., Kawchak, D. A., Goran, M. I., Ohene-Frempong, K., & Stallings, V. A. (2000). Total and resting energy expenditure in children with sickle cell disease. *Journal of Pediatrics, 136*, 73–79. doi: http://dx.doi.org/10.1016/S0022-3476(00)90053-2

Barnes, V.A., Treiber, F., & Johnson, M.H. (2004). Impact of transcendental meditation on ambulatory blood pressure in African-American adolescents. *American Journal of Hypertension, 17,* 366-369. doi: http://dx.doi.org/10.1016/j.amjhyper.2003.12.008

Bediako, S.M., Lattimer, L., Haywood, C., Jr., Ratanawongsa, N., Lanzkron, S., & Beach, M. C. (2011). Religious coping and hospital admissions among adults with sickle cell disease. *Journal of Behavioral Medicine, 34*(2), 120-127. doi: http://dx.doi.org/10.1007/s10865-010-9290-8

Benner-Carson, V. & Koenig, H.G. (2004). *Spiritual caregiving: Healthcare as a ministry.* Philadelphia: Templeton Foundation Press.

Bennett, E. (2011). Understanding growth failure on children with homyzygous sickle-cell disease. *Journal of Pediatric Oncology Nursing, 28*(2), 67-74. doi: http://dx.doi.org/10.1177/1043454210382421

Benore, E., Pargament, K.I., & Pendleton, S. (2008). An initial examination of religious coping in children with asthma. *The International Journal for the Psychology of Religion, 18,* 267-290. doi: http://dx.doi.org/10.1080/10508610802229197

Benson, P. L., & Roehlkepartain, E. C. (2008). Spiritual development: A missing priority in youth development. *New Directions for Youth Development,* 118, 13-28. doi: http://dx.doi.org/10.1002/yd.253

Benson, P. L., Roehlkepartain, E. C., & Rude, S. P. (2003). Spiritual development in childhood and adolescence: Toward a field of inquiry. *Applied Developmental Science, 7*(3), 204-212. doi: http://dx.doi.org/10.1207/S1532480XADS0703_12

Berges, I.M., Kuo, Y.F., & Markides, K.S. (2007). Attendance at religious services and physical functioning after stroke among older Mexican Americans. *Experimental Aging Research, 33,* 1-11. doi: http://dx.doi.org/10.1080/03610730601005893

Berntson, G.G., Norman, G.J., Hawkley, L.C., & Cacioppo, J.T. (2008). Spirituality and autonomic cardiac control. *Annals of Behavioral Medicine, 35*(2), 198-208. doi: http://dx.doi.org/10.1007/s12160-008-9027-x

Black, D.S., Milam, J. & Sussman, S. (2009). Sitting-meditation interventions among youth: A review of treatment efficacy. *Pediatrics (124),* 3, e532-541. doi: http://dx.doi.org/10.1542/peds.2008-3434

Black, P. H. (2003). The inflammatory response is an integral part of the stress response: implications for atherosclerosis, insulin resistance, type II diabetes and metabolic syndrome X. *Brain, Behavior, and Immunology, 17,* 350–364. doi: http://dx.doi.org/10.1016/s0889-1591(03)00048-5

Boswell, C., Cannon, S.B., & Miller, J. (2013). Student's perceptions of holistic care. *Nursing Education Perspectives, 34*(5), 329-333. doi: http://dx.doi.org/10.5480/1536-5026-34.5.329

Boyes, S. (2006). Individual art therapy with resistant adolescents. In S.L. Brooke (Ed.), *Creative arts therapies manual* (pp. 40-46). Springfield, IL: Charles C. Thomas.

Bridges, K.R. & Pearson, H.A. (2008). Sickle Cell Disease. *Anemias and other red cell disorders*. New York: McGraw-Hill.

Bull, A. & Gilles, M. (2007). Spiritual needs of children with complex healthcare needs in hospital. *Pediatric Nursing, 19*(9), 34-38. doi: http://dx.doi.org/10.7748/paed2007.11.19.9.34.c6283

Burdette, A.M. & Hill, T.D. (2009). Religious involvement and transitions into adolescent sexual activities. *Sociology of Religion, 70* (1), 28-48. doi: http://dx.doi.org/10.1093/socrel/srp011

Burns, V. E., Drayson, M., Ring, C. & Carroll, D. (2002). Perceived stress and psychological well-being are associated with antibody status after meningitis C conjugate vaccination. *Psychosomatic Medicine, 64,* 963–970. doi: http://dx.doi.org/10.1097/01.psy.0000038936.67401.28

Cacioppo, J.T., Hawkley, L.C, Rickett, E.M., & Masi, C.M., (2005). Sociality, Spirituality, and Meaning Making: Chicago Health, Aging, and Social Relations Study. *Review of General Psychology, 9* (2), 143-155. doi: http://dx.doi.org/10.1037/1089-2680.9.2.143

Cavendish, R., Luise, B.K., Russo, D., Mitzeliotis, C., Bauer, M., McPartlan Bajo, M.A., Calvino, C., Horne, K., & Medefindt J. (2004). Spiritual perspectives of nurses in the United States relevant for education and practice. *Western Journal of Nursing Research, 26* (2), 196-212. doi: http://dx.doi.org/10.1177/0193945903260815

Cepeda, M.L., Allen, F.H., Cepeda, N.J. & Yang, Y.M. (2000). Physical growth, sexual maturation, body image and sickle cell disease. *Journal of the National Medical Association, 92*(1), 10-14.

Children's Defense Fund (2011). The State of America's Children. Retrieved February 29, 2012 from http://www.childrensdefense.org/child-research-data-publications/data/state-of-americas-2011.pdf

Children's Defense Fund (2008). Retrieved April 1, 2010 from
http://www.childrensdefense.org/child-research-data-publications/data/state-of-americas-children-2008-report.html

Children's Memorial Hospital. Retrieved April, 2011 from
http://www.childrensmemorial.org

Claster, S. & Vichinsky, E.P. (2003). Managing sickle cell disease. *British Medical Journal, 15* (327), 1151-1155.
doi: http://dx.doi.org/10.1136/bmj.327.7424.1151

Colleen, D. & Barrere, C. (2009). The experience of environmental meditation in patients with cardiovascular disease. *Holistic Nursing Practice, 23*(6), 361-369.
doi: http://dx.doi.org/10.1097/hnp.0b013e3181bf381c

Compas, B.E., Jaser, S.S., Dunn, M.J., & Rodriguez, E.M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology, 8,* 455-480.
doi: http://dx.doi.org/10.1146/annurev-clinpsy-032511-143108

Cone, P.H. & Giske, T. (2013). Teaching spiritual care--a grounded theory study among undergraduate nursing educators. *Journal of Clinical Nursing, (13-14),* 1951-1960.
doi: http://dx.doi.org/10.1111/j.1365-2702.2012.04203.x

Conran, N. & Costa, F. (2009). Hemoglobin disorders and endothelial cell interactions. *Clinical Biochemistry, 42,* 1824-1838.
doi: http://dx.doi.org/10.1016/j.clinbiochem.2009.06.024

Cooper-Effa, M., Blount, W., Kaslow, N., Rothenberg, R., & Eckman, J. (2001). Role of spirituality in patients with sickle cell disease. *Journal of the American Board of Family Practice, 14* (2)*,* 116-122.

Cotton, S., Grossoehme, D.H., Bignall, W.R. & Weekes-Canu, J.C., 2013. Should my provider pray with me? Perspectives of urban adolescents with asthma on addressing religious and spiritual issues in hypothetical clinical situations. *Journal of Religion and Health.*

Cotton, S., Grossoehme, D., & McGrady, M.E. (2012). Religious coping and the use of prayer in children with sickle cell disease. *Pediatric Blood Cancer, 58* (2), 244-249.
doi: http://dx.doi.org/10.1002/pbc.23038

Cotton, S., Grossoehme, D., Rosenthal, S.L., McGrath, M.E., Roberts, Y.H., Hines, J., Yi, M.S. & Tsevat, J. (2009). Religious/Spiritual coping in adolescents with sickle cell disease. *Journal of Pediatric Hematology Oncology, 31* (5), 313-318.
doi: http://dx.doi.org/10.1097/mph.0b013e31819e40e3

Cotton, S., Kudel, I., Roberts, Y.H., Palleria, H., Tsevat, J., Succop, P., & Yi, M.S. (2009). Spiritual well-being and mental health outcomes in adolescents with or without inflammatory bowel disease. *The Journal of Adolescent Health, 44*(5), 486-492.
doi: http://dx.doi.org/10.1016/j.jadohealth.2008.09.013

Cotton, S., Puchalski, C.M, Sherman, S.N., Mrus, J.M., Peterman, A.H., Feinberg, J., Pargament, K. I., Justice, A.C., Leonard, A.C., & Tsevat, J. (2006). Spirituality and religion in patients with HIV/AIDS. *Journal of General Internal Medicine*, *21,* S5-S13.
doi: doi: http://dx.doi.org/10.1111/j.1525-1497.2006.00640.x

Cotton, S., Weekes, J.C., McGrady, M.E. (2012). Spirituality and religiosity in urban adolescents with asthma. *Journal of Religion and Health, 51*(1), 118-31.
doi: http://dx.doi.org/10.1007/s10943-010-9408-x

Cotton, S., Zebracki, K., Rosenthal, S.L., Tsevat, J. & Drotar, D. (2006). Religion/spirituality and adolescent health outcomes: A review. *Journal of Adolescent Health, 38,* 472-480.Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches.* Thousand Oaks, CA: SAGE.
doi: http://dx.doi.org/10.1016/j.jadohealth.2005.10.005

Davis, T.L., Kerr, B.A., & Kurpius, S.E.R. (2003). Meaning, purpose, and religiosity in at-risk youth: the relationship between anxiety and spirituality. *Journal of Psychology and Theology, 31*(4):356–65.

DeBaun, M.R. & Telfair, J. (2012). Transition and sickle cell disease. *Pediatrics, 130*, 926-936.
doi: http://dx.doi.org/10.1542/peds.2011-3049

Dedert, E.A., Studts, J.A., Weissbecker, I., Salmon, P.G., Banis, P.L., & Sephton, S.E. (2004). Religiosity may help preserve the cortisol rhythm in women with stress related illness. *International Journal of Psychiatry in Medicine, 34* (1), 61-77. doi: http://dx.doi.org/10.2190/2y72-6h80-bw93-u0t6

Delaney, C. & Barrere, C. (2009). Ecospirituality: the experience of environmental meditation in patients with cardiovascular disease. *Holistic Nursing Practice, 23*(6):361-9. doi: http://dx.doi.org/10.1097/hnp.0b013e3181bf381c

Dennis-Antwi, J. A., Culley, L., Hiles, D. R., & Dyson, S. M. (2011). 'I can die today, I can die tomorrow': lay perceptions of sickle cell disease in Kumasi, Ghana at a point of transition. *Ethnicity & Health*, *16*(4/5), 465-481. doi: http://dx.doi.org/10.1080/13557858.2010.531249

Denton, M. L., Pearce, L.D., & Smith, C. (2008). *Religion and Spirituality On the Path Through Adolescence, Research Report Number 8.* National Study of Youth and Religion, University of North Carolina at Chapel Hill. Retrieved November 30, 2011, http://www.youthandreligion.org/sites/youthandreligion.org/files/imported/publications/docs/w2_pub_report_final.pdf/

Denzin, N.K. & Lincoln, Y.S. (1998). Methods of collecting and analyzing empirical materials. In Denzin, N.K. & Lincoln, Y.S. (Eds.). Collecting and interpreting qualitative materials. Thousand Oaks, CA: SAGE.

Denzin, N.K. & Lincoln, Y.S. (2011). The discipline and practice of qualitative research. In Denzin, N.K. &Lincoln, Y.S. (Eds.), *The SAGE handbook of qualitative research.* Thousand Oaks, CA: SAGE.

Dew, R.E., Daniel, S.S., Goldston, D.B. & Koenig, H.G. (2004). Religion, spirituality, and depression in adolescent psychiatric patients. *The Journal of Nervous and Mental Disease, 196* (3), 247-251. doi: http://dx.doi.org/10.1097/nmd.0b013e3181663002

Diggs, L. M. (1973). Anatomic lesions in sickle cell disease. In Abramson, H., Bertles, J.F. & Wethers, D.L. (Eds.), *Sickle cell disease: Diagnosis, management, education, and research*. St. Louis: C. V. Mosby.

Draucker, C.B. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing, 30*(2), 360-73.
doi: http://dx.doi.org/10.1046/j.1365-2648.1999.01091.x

Dunston, F.J. (2006). Health Disparities in Children. In Satcher, D. & Pammies, R.J. (Eds.), *Multicultural medicine and health disparities.* New York, NY: McGraw-Hill.

Edwards, C.L., Scales, M.T., Loughlin, C., Bennett, G.G.Harris-Peterson, S., De Castro. L., Whitworth. E., Abrams, M., Feliu, M., Johnson, S., Wood, M., Harrison, O., Killough, A., et al. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12* (3), 171-179.
doi: http://dx.doi.org/10.1207/s15327558ijbm1203_6

Elander, J., Beach, M., & Haywood, C. (2011). Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. *Ethnicity & Health*, *16*(4/5), 405-421.
doi:10.1080/13557858.2011.555520

Elixhauser, A. & Steiner, C. (2013). *Readmissions to U.S hospitals by diagnosis, 2010* (Statistical brief #153). Retrieved from
http://www.hcup-us.ahrq.gov/reports/statbriefs/sb153.pdf

Enstrom, J.E. & L. Breslow (2008). Lifestyle and reduced mortality among active California Mormons, 1980-2004." *Preventive Medicine, 46*(2), 133-136.
doi: http://dx.doi.org/10.1016/j.ypmed.2007.07.030

Erikson, E. (1978). *Identity youth in crisis.* New York, NY: W.W. Norton.

Fetzer Institute (2003). Multidimensional measure of religiousness/spirituality for use in health research: A report of the Fetzer Institute & National Institute on Aging Working Group. Kalamazoo, MI: Fetzer Institute.

Forte, L.R (1997). The meaning of hope to family caregivers of children with sickle cell disease. D.S.N., 230 p. University of Alabama at Birmingham.

Fowler, J. (1981). *Stages of faith: The psychology of human development and the quest for meaning. San Francisco: Harper & Row.*

Frisch, N.C. (2001). Standards for holistic nursing practice: A way to think about care that includes complementary and alternative modalities. *Online Journal of Issues in Nursing*, *6* (2), available http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Volume62001/No2May01/HolisticNursingPractice.aspx

Gallison, B.S., Xu, Y., Jurgens, C.Y. & Boyle, S.M. (2013). Acute care nurses' spiritual care practices. *Journal of Holistic Nursing, 31*(2), 95-103. doi: http://dx.doi.org/10.1177/0898010112464121

George, L.K., Larson, D.B., Koenig, H.G., & McCullough, M.E. (2000). Spirituality and Health: What we know, what we need to know. *Journal of Social and Clinical Psychology, 19*(1), *102-116.* doi: http://dx.doi.org/10.1521/jscp.2000.19.1.102

Gil, K.M., Anthony, K.K., Carson, J.W., Redding-Lallinger, R., Daeschner, C.W., & Ware, R.E. (2001). Daily coping practice predicts treatment effects in children with sickle cell disease. *Journal of Pediatric Psychology, 26*(3), 163-173. doi: http://dx.doi.org/10.1093/jpepsy/26.3.163

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Gilligan, C. & Attanucci, J. (1988). Two moral orientations. In Gilligan, C., Ward, J.V., & McClean-Taylor, J., Bardige, B. (Eds.), *Mapping the moral domain (pp.73-86).* Cambridge, MA: Harvard University Press.

Girard, G.A. (2009). Poverty and inequity in adolescent health care. *Adolescent Medicine: State of the art reviews, 20* (3), 887-899. doi: http://dx.doi.org/10.1016/s0140-6736(88)92362-8

Glaser, R. & Kiecolt-Glaser, J.K. (2005). Stress-induced immune dysfunction: Implications for health. *Immunology, 5,* 243-251. doi: http://dx.doi.org/10.1038/nri1571

Glaser, R., Robles, T., Sheridan, J., Malarkey, W. B. & Kiecolt-Glaser, J. K. (2003). Mild depressive symptoms are associated with amplified and prolonged inflammatory responses following influenza vaccination in older adults. *Archives of General Psychiatry 60*, 1009–1014.
doi: http://dx.doi.org/10.1001/archpsyc.60.10.1009

Glaser, R., Sheridan, J. F., Malarkey, W. B., MacCallum, R. C. & Kiecolt-Glaser, J. K. (2000). Chronic stress modulates the immune response to a pneumococcal pneumonia vaccine. *Psychosomatic Medicine, 62,* 804–807.
doi: http://dx.doi.org/10.1007/bf02883323

Goleman, D. (1988). *The meditative mind: The varieties of meditative experience.* New York, NY: Tarcher/Putnam.

Good, M. & Willoughby, T. (2006). The role of spirituality versus religiosity in adolescent psychosocial adjustment. *Journal of Youth and Adolescence, 35*(1), 41-55.
doi: http://dx.doi.org/10.1007/s10964-005-9018-1

Griffin, M. J., & Chen, E. (2006). Perceived control and immune and pulmonary outcomes in children with asthma. *Psychosomatic Medicine, 68*, 493–499.
doi: http://dx.doi.org/10.1097/01.psy.0000221367.96439.da

Grossoehme, D.H., Opipari-Arrigan, L., Thurmond, S., & Seid, M. (2011). Relationship of adherence determinants and parental spirituality in cystic fibrosis. *Pediatric Pulmonology, 47* (6), 558-556.
doi: http://dx.doi.org/10.1002/ppul.21614

Grossoehme, D.H., Wandyke, R. & Seid, M. (2008). Spirituality's role in chronic disease self-management: Sanctification of the body in families dealing with cystic fibrosis. *Journal of Health Care Chaplaincy, 15:* 149-158.
doi: http://dx.doi.org/10.1080/08854720903163312

Guba, E.G. (1996). What happened to me on the road to Damascus. In L. Heshusius & K. Ballard (Eds.), *From positivism to interpretivism and beyond: Tales of transformation in educational and social research (pp. 43-49).* New York: Teachers College Press.

Guba, E.G. & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *The SAGE handbook of qualitative research (3rd ed., pp. 191-215).* Thousand Oaks, CA: SAGE.

Haase, J.E. (2004). The adolescent resilience model as a guide to interventions, *Journal of Pediatric Oncology Nursing, 21,* 289-299. doi: http://dx.doi.org/10.1177/1043454204267922

Haase, J.E. & Phillips, C.R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing, 21*(3), 145-149. doi: http://dx.doi.org/10.1177/1043454204264385

Haglund, KA., & Fehring, R.J. (2010). The association of religiosity, sexual education, and parental factors with risky sexual behaviors among adolescents and young adults. *Journal of Religion and Health,* 49, 460-472. doi: http://dx.doi.org/10.1007/s10943-009-9267-5

Hampton, D.M., Hollis, D.E., Lloyd, D.A., Taylor, J. & McMillan, S.C. (2007). Spiritual needs of patients with advanced cancer. *American Journal of Hospice and Palliative Medicine, 24*(1), 42-48. doi: http://dx.doi.org/10.1177/1049909106295773

Harris, K., Florey, F., Tabor, J., Bearman, P., Jones, J., & Udry, R. (2003). *The National Longitudinal Study of Adolescent Health: Research Design.* www.cpc.unc.edu/projects/addhealth/design

Harris, T.B., Ferruci, L., Tracy, R.P., Corti, M.C., Wacholder, S., Ettinger, W.H., Heimovitz, H., Cohen, H.J., & Wallace, R. (1999). Associations of elevated interleukin-6 and C-reactive protein levels with mortality in the elderly. *American Journal of Medicine, 106*, 506–512. doi: http://dx.doi.org/10.1016/s0002-9343(99)00066-2

Harrison, M.O., Edwards, C.L., Koenig, H.G., Bosworth, H. B., Decastro, L. & Wood, M. (2005). Religiosity/Spirituality and pain in patients with sickle cell disease. *The Chicago Journal of Nervous & Mental Disease, 193*(4), 250-257. doi: http://dx.doi.org/10.1097/01.nmd.0000158375.73779.50

Hay, D., Reich, K.H., & Utsch, M. (2011). Spiritual Development: Intersections and Divergence with Religious Development. In Roehlkepartain, E.C., Benson, P.L. & Scales, P.C. (Eds.), *Handbook of Identity Theory and Research* (pp. 46-59). New York, NY: Springer.

Hay, D., & Nye, R. (2006). Nurturing the spirit of the child. In Hay, D. & Bye, R. (Eds.), *The spirit of the child (2nd ed., pp.146-159).* London: Jessica Kingsley Publishers.

Hay, D., & Nye, R. (2006). What is spirituality and why is it important? In Hay, D. & Nye, R. (Eds.), *The spirit of the child (2nd ed., pp. 17-32).* London: Jessica Kingsley Publishers.

Hay, D., & Nye, R. (2006). Children's spirituality: What we know already. In Hay, D. & Bye, R. (Eds.), *The spirit of the child (2nd ed., pp. 49-62).* London: Jessica Kingsley Publishers.

Healthcare Cost and Utilization Project (HCUP) (2006). *Sickle cell disease patients in U.S. Hospitals, 2004.* Rockville, MD.: Agency for Healthcare Research and Quality (AHQR) Statistical Brief No. 21.

Heberman, R.B. (2002). Stress, natural killer cells, and cancer. In H.G. Koenig, & H.J. Cohen (Eds), The link between religion and health: Psychoneuroimmunology and the faith factor. New York, NY: Oxford.

Hendricks-Ferguson, V. (2008). Hope and spiritual well-being in adolescents with cancer. *Western Journal of Nursing Research, 30*(3), 385-401. doi: http://dx.doi.org/10.1177/0193945907303045

Hesse-Biber, S.N. & Leavy, P. (2006). *The practice of qualitative research.* Thousand Oaks, CA: Sage.

Hodge DR, Cardenas P, Montoya H. (2001). Substance use: spirituality and religious participation as protective factors among rural youths. *Social Work Research, 25*(3):153– 62. doi: http://dx.doi.org/10.1093/swr/25.3.153

Holder, D.W., DuRant, R.H., Harris, T.L., Daniel, J.H., Obeidallah, D. & Goodman, E. (2000). The association between adolescent spirituality and voluntary sexual activity. *Journal of Adolescent Health, 26*(4), 295-302. doi: http://dx.doi.org/10.1016/s1054-139x(99)00092-0

Ignativicus, D.D. & Workman, M.L. (2006). *Medical-surgical nursing: Critical thinking for collaborative care.* St. Louis, MI: Elsevier.

Ironson, G., Solomon, G.F., Balbin, E.G., O'Cleirigh, C., George, A., Kumar, M., Larson, D., & Woods, T. (2002). The Ironson-Woods spirituality/religiousness index is associated with long survival, health behaviors, less distress, and low cortisol in people with HIV/AIDS. *Annals of Behavioral Medicine, 24*(1), 34-48. doi: http://dx.doi.org/10.1207/s15324796abm2401_05

Jackson, L., Roller-White, C., O'Brien, K., DiLorenzo, P., Cathcart, E., Wolf, M., Bruskas, D., Pecora, P., Nix-Early, V., & Cabrera, J. (2010). Exploring spirituality among youth in foster care: Findings from the Casey Field Office Mental Health Study. *Child and Family Social Work, 15,* 107-117. doi: http://dx.doi.org/10.1111/j.1365-2206.2009.00649.x

Jenerette, C.M. & Phillips, R.C.S. (2006). An examination of differences in intrapersonal resources, self-care management, and health outcomes in older and younger adults with sickle cell disease. *Southern Online Journal of Nursing Research, 7* (3), 1-24.

Johnson, B.R. (2008). A tale of two religious effects: Evidence for the protective and and prosocial impact of organic religion. In K.K. Kloine (Ed.), *Authoritative communities: The scientific case for nurturing the whole child* (pp. 187-226). New York: Springer.

Joint Commission for the Accreditation of Hospital Organizations, http://www.jointcommission.org/standards_information/jcfaqdetails.aspx?StandardsFaqId=290&ProgramId=1 (last revised November 24, 2008).

Joint Commission for the Accreditation of Hospital Organizations, http://www.jointcommission.org/assets/1/18/jconline_Mar_30_11.pdf (last revised March 30, 2011).

Kauf, T.L., Coates, T.D., Huazhi, L., Mody-Patel, N., & Hartzema, A.G. (2009). The costs of health care for children and adults with sickle cell disease. *American Journal of Hematology, 84*(6), 323-327. doi: http://dx.doi.org/10.1002/ajh.21408

Kiecolt-Glaser, J.K., Loving, T.J., Stowell, J.R., Malarkey, W.B., Lemeshow, S., Dickinson, S.L., & Glaser, R. (2005). Hostile marital interactions, proinflammatory cytokines production, and wound healing. *Archives of General Psychiatry, 62* (12), 1377-1384. doi: http://dx.doi.org/10.1001/archpsyc.62.12.1377

King, D.E., Mainous, A.G., & Pearson, W.S. (2002). C - reactive protein, diabetes, and attendance at religious services. *Diabetes Care, 25,* 1172-1176. doi: http://dx.doi.org/10.2337/diacare.25.7.1172

Kloosterhouse, V. & Ames, B. (2002). Families' use of religion/spirituality as a psychosocial resource. *Holistic Nursing Practice, 16*(5), 61-75. doi: http://dx.doi.org/10.1097/00004650-200210000-00011

Koenig, H.G. (2007). *Spirituality in patient health care (2nd ed.).* Templeton Press: Philadelphia, PA.

Koenig, H.G. & Cohen, H.J. (2002). Psychological stress and autoimmune disease. In H.G. Koenig, & H.J. Cohen (Eds), *The link between religion and health: Psychoneuroimmunology and the faith factor.* New York, NY: Oxford.

Koenig, H.G. & Cohen, H.J. (2002). Psychosocial factors, immunity, and wound healing. In H.G. Koenig, & H.J. Cohen (Eds), *The link between religion and health: Psychoneuroimmunology and the faith factor.* New York, NY: Oxford.

Koenig, H.G., George, L.K., Titus, P., & Meador, K.G. (2004). Religion, spirituality, acute hospital and long-term care use by older patients. *Archives of Internal Medicine, 164,* 1579-1585. doi: http://dx.doi.org/10.1001/archinte.164.14.1579

Koenig, H.G., Meador, K.G., & Parkerson, G. (1997). Religion index for psychiatric research. American Journal of Psychiatry 154 (6): 885-886 (also, see Hill P & Hood R (Eds.), Measures of Religious Behavior. Birmingham, Al: Religious Education Press, 1998).

Kohlberg, L. (1984). *The Psychology of Moral Development: The Nature and Validity of Moral Stages.* San Francisco, CA: Harper & Row. Thousand Oaks, CA: SAGE.

Labbe', E., Herbert, D., & Haynes, J. (2005). Physicians' attitudes and practices in sickle cell disease pain management. *Journal of Palliative Care, 21*(4), 246-251.

Ladd, G. (1999). Peer relationships and social competence during early and middle childhood. *Annual Review of Psychology, 50,* 333-359. doi: http://dx.doi.org/10.1146/annurev.psych.50.1.333

Lambert, K.G. & Hinsley, C.H. (2011). Psychoneuroimmunology. In K.G. Lambert & C.H. Hinsley (Eds.), *Clinical neuroscience: Psychopathology and the brain (2nd ed., pp. 391-419).* New York, NY: Oxford University Press.

Lane, M.R. (2005). Creativity and spirituality in nursing. *Holistic Nursing Practice, 19* (3), 122-125. doi: http://dx.doi.org/10.1097/00004650-200505000-00008

Lane, P.A., Buchanan, G.R., Desposito, F., Pegelow, C.H., Vichinsky, E.P., Wethers, D.L., & Woods, G.M. (2002). Health supervision for children with sickle cell disease. *Pediatrics, 109,* 526-535. doi: http://dx.doi.org/10.1542/peds.109.3.526

Larson, D.B., Swyers, J.P., & McCullough, M.E. (1998). *Scientific research on spirituality and health: A consensus report.* Rockville, MD: National Institute for Healthcare Research.

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage

Lincoln, Y.S., Lynham, S.A., & Guba, E.G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N.K. Denzin & Y.S.

Lincoln (Eds.), *The SAGE handbook of qualitative research (4th ed., pp.97-128).*

Lowe, J. (2002). Balance and harmony through connectedness: The intentionality of Native American nurses. *Holistic Nursing Practice, 16* (4), 4-11. doi: http://dx.doi.org/10.1097/00004650-200207000-00004

Lupien, S.J., King, S., Meaney, S.J., & McEwen, B.S. (2001). Can poverty get under your skin? Basal cortisol levels and cognitive function in children from low and and high socioeconomic income status. doi: http://dx.doi.org/10.1017/s0954579401003133

Lynn, C.D., Paris, J.J., Frye, C.A., & Schell, L.M. (2011). Glossolalia is associated with differences in biomarkers of stress and arousal among Apostolic Pentecostals. *Religion, Brain, & Behavior, 1*(3), 173-191. doi: http://dx.doi.org/10.1080/2153599x.2011.639659

Lynn, C.D., Paris, J., Frye, C.A., & Schell, L.M. (2010). Salivary alpha-amylase and cortisol among Pentecostals on a worship and nonworship day. *American Journal of Human Biology*, *22*, 819-822. doi: http://dx.doi.org/10.1002/ajhb.21088

Lyon, M.E., Townsend-Akpan, C., & Thompson, A. (2001). Spirituality and end-of-life care for an adolescent with AIDS. *AIDS Patient Care and STDs*, 15, 555–560. doi: http://dx.doi.org/10.1089/108729101753287630

McPherson, M., Thaniel, L., & Minniti, C.P. (2009). Transition of patients with sickle cell disease from pediatric to adult care: assessing patient readiness. *Pediatric Blood Cancer*, *52* (7), 838–841. doi: http://dx.doi.org/10.1002/pbc.21974

Maes, M., Ombelet, W., De Jongh, R., Kenis, G. & Bosmans, E. (2001). The inflammatory response following delivery is amplified in women who previously suffered from major depression, suggesting that major depression is accompanied by a sensitization of the inflammatory response system. *Journal of Affective Disorders, 63*, 85–92. doi: http://dx.doi.org/10.1016/s0165-0327(00)00156-7

Males, M. (2009). Does the adolescent brain make risk-taking inevitable? A skeptical appraisal. *Journal of Adolescent Research, 24*(1), 3-20. doi: http://dx.doi.org/10.1177/0743558408326913

Mann-Jiles, V. & Lynn-Morris, D. (2009). Quality of life of adult patients with sickle cell disease. *Journal of the American Academy of Nurse Practitioners, 21*(6), 340-349. doi: http://dx.doi.org/10.1111/j.1745-7599.2009.00416.x

Marini, I. & Glover-Graf, N.M. (2011). Religiosity and spirituality among persons with spinal cord injury: Attitudes, beliefs, and practices. *Rehabilitation Counseling Bulletin, 54* (2), 82-92. doi: http://dx.doi.org/10.1177/0034355210368868

Matthews, K.A., Salomon, K., Brady, S.S., & Allen, M.T. 2003. Cardiovascular reactivity to stress predicts future blood pressure in adolescents. *Psychosomatic Medicine, 65,* 410–415. doi: http://dx.doi.org/10.1097/01.psy.0000057612.94797.5f

Maxwell, J.A. (2005). *Qualitative research design: An interactive approach (2nd ed.).* Sage: Thousand Oaks, CA.

McClish, D.K., Smith, W.R., Dahman, B.A., Levenson, J.L., Roberts, J.D., Penberthy, L.T., Aisiku, I.P., Roseff, S.D., & Bovbjerg, V.E. (2009). Pain site frequency and location in sickle cell disease: the PiSCES project. *Pain*, *145*(1-2), 246–251. doi: http://dx.doi.org/10.1016/j.pain.2009.06.029

Merkes, M. (2010). Mindfulness-based stress reduction for people with chronic diseases. *Australian Journal of Primary Health, 16*(3), 200-10. doi: http://dx.doi.org/10.1071/py09063

Mertens, D.M. (2009). *Transformative Research and Evaluation,* New York: Guilford Press.

Michlitsch, J.G. & Walters, M.C. (2008). Recent advances in bone marrow transplantation in hemoglobinopathies. *Current Molecular Medicine, 8,* 675-689. doi: http://dx.doi.org/10.2174/156652408786241393

Mihaljević S., Vuksan-Ćusa, B., Marcinko, D., Koić, E., Kusević, Z., & Jakovljević, M. (2011). Spiritual well-being, cortisol, and suicidality in Croatian war veterans suffering from PTSD. *Journal of Religion and Health, 50,* 464-473. doi: http://dx.doi.org/10.1007/s10943-010-9383-2

Miles, M.B. & Huberman, A.M. (1994). Qualitative Data Analysis (2nd edition). Thousand Oaks, CA: Sage Publications.

Miller, G. & Chen, E. (2007). Unfavorable socioeconomic conditions in early life presage expression of proinflammatory phenotype in adolescence. *Psychsomatic Medicine, 69* (5), 402-409. doi: http://dx.doi.org/10.1097/psy.0b013e318068fcf9

Miller, G.E. Chen, E. & Parker, K. (2011). Psychological stress in childhood and susceptibility to the chronic diseases of aging: Moving towards a model of behavioral and biological mechanisms. *Psychological Bulletin, 137* (6), 959-997. doi: http://dx.doi.org/10.1037/a0024768

Miller, W.L., & Crabtree, B.F. (1992). Primary care research: A multimethod typology and qualitative road map. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research*. Newbury Park, CA: Sage.

Miller, W.R., & Thoresen, C.E. (2003). Spirituality, religion, and health: An emerging research field. *American Psychologist, 58,* 24-35. doi: http://dx.doi.org/10.1037/0003-066x.58.1.24

Mitchell, M.J., Carpenter, G.J.O., Crosby, L.E., Bishop, C.T., Hines, J., & Noll, J. (2009). Growth status in children and adolescents with sickle cell disease. *Pediatric Hematology & Oncology, 26* (4), 202-215. doi: http://dx.doi.org/10.1080/08880010902896882

Moody, K., Mannix, M.M., Furnari, N., Fischer, J., Kim, M., & Moadel, A. (2011). Psychosocial needs of ethnic minority, inner city, pediatric cancer patients. *Support Care Cancer, 19,* 1403-1410. doi: http://dx.doi.org/10.1007/s00520-010-0966-y

Moore, L.W. & Miller, M. (1999). Initiating research with doubly vulnerable populations. *Journal of Advanced Nursing, 30* (5), 1034-1040. doi: http://dx.doi.org/10.1046/j.1365-2648.1999.01205.x

Munhall, P.L. (2001). *Nursing research* (3rd ed.)*.* Columbia, SC: Jones & Bartlett.

Nabhan-Warren, K. (2011). La Virgen, she watches over us. In S.B. Ridgely (Ed.), The study of children in religions: A methods handbook. New York, NY: New York University Press.

Narayanasamy, A. (2004). The puzzle of spirituality for nursing: A guide to practical assessment. *British Journal of Nursing, 13* (19), 1140-1144.

National Center on Birth Defects and Developmental Disabilities. Center for Disease Control and Prevention (2012). Sickle cell disease and thalassemia. Retrieved February 25, 2013 from http://www.cdc.gov/ncbddd/aboutus/blood-disorders-sicklecell.html

Nassau, J.H., Tien, K., & Fritz, G.K. (2008). Review of the literature: Integrating psychoneuroimmunology into pediatric chronic illness interventions. *Journal of Pediatric Psychology, 33*(2), 195-207. doi: http://dx.doi.org/10.1093/jpepsy/jsm076

Neuman, B.M. (1989). *The Neumann systems model* (2nd ed). Norwalk, CT: Appleton & Lange.

Neuman, B.M. (1995). *The Neuman systems model* (3rd ed). Stamford, CT: Appleton & Lange.

Newland, J. (2008). Factors influencing independence in adolescents with sickle cell disease. *Journal of Child and Adolescent Psychiatric Nursing, 21* (3), 177-185. doi: http://dx.doi.org/10.1111/j.1744-6171.2008.00149.x

North American Nursing Diagnosis Association (2001). *NANDA nursing diagnoses: Definitions and classification* 2001-2002. Philadelphia: Publisher.

O'Brien, M.E. (2004). A nurse's handbook of spiritual care. Jones and Bartlett: Sudbury, MA.

O'Brien, S.H., Klima, J., Reed, S., Chisolm, D., Schwarz, E.B., & Kelleher, K.J. (2011). Hormonal contraception use and pregnancy in adolescents with sickle cell disease: Analysis of Michigan Medicaid claims. *Contraception, 83*(2), 134-7. doi: http://dx.doi.org/10.1016/j.contraception.2010.06.017

O'Connell-Edwards, C. F., Edwards, C. L., Pearce, M., Waccholtz, A. B., Wood, M., Muhammad, M., Leach-Beale, B., Shelby, R., McDougald, C.S., Harrison, M.O., Feliu, M., Edwards, L.Y., Whitfield, K.E., Merritt, M., Wellington, C., Byrd, G., McNeil, J.C., Edmonds, H., & Robinson, E. (2009). Religious coping and pain associated with sickle cell disease: Exploration of a non-linear model. *Journal of African American Studies, 13,* 1-13. doi: http://dx.doi.org/10.1007/s12111-008-9063-4

Pargament, K.I. (1997). *The psychology of religion and coping*: *Theory, research and practice.* New York, NY: The Guilford Press.

Pargament, K.I., Koenig, H., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology, 9*(6), 713-730. doi: http://dx.doi.org/10.1177/1359105304045366

Parry, C. & Chessler, M.A. (2005). Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qualitative Health Research, 15* (8), 1055-1073. doi: http://dx.doi.org/10.1177/1049732305277860

Pendleton, S.M., Cavalli, K.S., Kenneth, B.A., Pargament, K.I. & Nasr, S.Z. (2002). Religious/spiritual coping in childhood cystic fibrosis: A qualitative study. *Pediatrics, 109*(1), 1-11. doi: http://dx.doi.org/10.1542/peds.109.1.e8

Petersen, A. (2008). Spiritual development in adolescence: Toward enriching theories, research, and professional practice. *New Directions for Youth Development, 118,* 119-130. doi: http://dx.doi.org/10.1002/yd.266

Piaget, J. (1954). *The Origins of Intelligence in Children.* New York, NY: International Universities Press.

Pinckney, R.B. & Stuart, G.W. (2004). Adjustment difficulties of adolescents with sickle cell disease. *Journal of Child and Adolescent Psychiatric Nursing, 17*(1), 5-12. doi: http://dx.doi.org/10.1111/j.1744-6171.2004.00005.x

Pike, S. (2011). Religion and youth in American culture. In S.B. Ridgely (Ed.), The study of children in religions: A methods handbook. New York, NY: New York University Press.

Platt, O.S., Brambilla, D.J., Rosse, W.F., Milner, P.F., Castro, O., Steinberg, M.H., & Klug, P. (1994). Mortality in sickle cell disease. Life Expectancy and risk factors for early death. *New England Journal of Medicine, 330*(23), 1639-1644. doi: http://dx.doi.org/10.1056/nejm199406093302303

Price, V.E., Blanchette, V.S., & Ford-Jones, E.L. (2007). The prevention and management of infections in children with asplenia or hyposplenia. *Infectious Disease Clinics of North America, 21*(3), 697-710. doi: http://dx.doi.org/10.1016/j.idc.2007.07.002

Puchalski, C. & Romer, A.L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine, 3* (1), 129-137. doi: http://dx.doi.org/10.1089/jpm.2000.3.129

Puffer, E.S., Schatz, J.C., & Roberts, C.W. (2010). Relationships between somatic growth and cognitive functioning in young children with sickle cell disease. *Journal of Pediatric Psychology, 35* (8), 892-904. doi: http://dx.doi.org/10.1093/jpepsy/jsp124

Quinn, C.T., Rogers, Z.R., McCavit, T.L., & Buchanan, G.R. (2010). Improved survival of children and adolescents with sickle cell disease. *Blood, 115* (17), 3447-3452. doi: http://dx.doi.org/10.1182/blood-2009-07-233700

Quinn, J. (2008). Perspectives on spiritual development as part of youth development. *New Directions for Youth Development, 118,* 73-78. doi: http://dx.doi.org/10.1002/yd.257

Rabin, B. (2002). Understanding how stress affects the physical body. In
    H.G. Koenig, & H.J. Cohen (Eds.), *The link between religion and health:
    Psychoneuroimmunology and the faith factor, pp. 43-68.* New York, NY: Oxford.

Rankin, E.A. & DeLashmutt, M.B. (2006). Finding spirituality and nursing presence: The
    student's challenge. *Journal of Holistic Nursing, 24* (4), 282-288.
    doi: http://dx.doi.org/10.1177/0898010106294423

Ray, O. (2004). How the mind hurts and heals the body. *The American Psychologist*, 59,
    29–40.
    doi: http://dx.doi.org/10.1037/0003-066x.59.1.29

Reddin, C. Cerrentano, E., & Tanabe, P. (2011). Sickle cell disease management in the
    emergency department: What every emergency nurse should know. *Journal of
    Emergency Nursing, 37*(4), 341-345.
    doi: http://dx.doi.org/10.1016/j.jen.2010.04.014

Reed, P.G. (1992). An emerging paradigm for the investigation of spirituality in nursing.
    Research in Nursing and Health, 15, 349-357.
    doi: http://dx.doi.org/10.1002/nur.4770150505

Rees, D.C., Williams, T.N. & Gladwin, M.T. (2010). Sickle cell disease. *The Lancet,
    9757,* 2018-2031.
    doi: http://dx.doi.org/10.1016/s0140-6736(10)61029-x

Regnerus, M.D. (2003). Religion and positive adolescent outcomes: A review of research
    and theory. *Review of Religious Research 44*, 394–413.
    doi: http://dx.doi.org/10.2307/3512217

Regnerus, M.D., & Burdette, A. (2006). Religious change and adolescent family
    dynamics, *The Sociological Quarterly*, *47,* 175-194.
    doi: http://dx.doi.org/10.1111/j.1533-8525.2006.00042.x

Regnerus, M.D. & Uecker, J. (2006). Finding faith, losing faith. The prevalence and
    context of religious transformations during adolescence. *Review of Religious
    Research, 47,* 217-237.

Rew, L. & Wong ,Y.J. (2006). A systematic review of associations among religiosity/spirituality and adolescent health attitudes and behaviors. *Journal of Adolescent Health*, *38*, 433– 442.
doi: http://dx.doi.org/10.1016/j.jadohealth.2005.02.004

Rhodes, M., Akoehoue, S.A., Shankar, S.M., Qi An, A, & Yu, C. (2009). Growth patterns in children with sickle cell anemia during puberty. *Pediatric Blood & Cancer, 53* (4), 635-641.
doi: http://dx.doi.org/10.1002/pbc.22137

Reynolds, N., Mrug, S., & Guion, K. (2013). Spiritual coping and psychosocial adjustment of adolescents with chronic illness: The role of cognitive attributions, age, and disease group. *Journal of Adolescent Health, 52*(5), 559-565.
http://dx.doi.org/10.1016/j.jadohealth.2012.09.007

Rippentrop, A.E., Altmaier, E.M., Chen, J.J., Found, E.M., & Keffala, V.J. (2005). The relationship between religion/spirituality and physical health, mental health, and pain in a chronic pain population. *Pain, 116,* 311-321.
doi: http://dx.doi.org/10.1016/j.pain.2005.05.008

Roehlkepartain, E. C., Benson, P. L., King, P.E., & Wagener, L.M. (2006). Spiritual development in childhood and adolescence: Moving to the scientific mainstream. In Roehlkepartain, E.C., King, P.E., Wagener, L. & Benson, P.L. (Eds.), *The handbook of spiritual development in childhood and adolescence*. Thousand Oaks, CA: Sage.

Roehlkepartain, E.C., Benson, P.L. & Scales, P.C. (2011). Spiritual Identity: Contextual Perspectives. In Schwartz, S.J., Luyckx, K., & Vignoles, V.L. (Eds.), *Handbook of Identity Theory and Research* (pp. 545-562). New York, NY: Springer.

Roehlkepartain, E. C., Benson, P. L., Scales, P. C., Kimball, L., & King, P. E. (2008). *With their own voices: A global exploration of how today's young people experience and think about spiritual development*. Minneapolis, MN: Search Institute.

Rousseau, P. (2003). Spirituality and the dying patient. *Journal of Clinical Oncology, 21* (9S), 54s-56s.
doi: http://dx.doi.org/10.1200/jco.2003.01.171

Sanchez, C.E., Schatz, J., & Roberts, C.W. (2010). Cerebral blood flow velocity and language functioning in pediatric sickle cell disease. *Journal of International Neuropsychological Society, 16* (2), 326-334. doi: http://dx.doi.org/10.1017/s1355617709991366

Sandberg, S., Paton, J. Y., Ahola, S., McCann, D. C., McGuinnes, D., Hilary, C. R., & Oja, H. (2000). The role of acute and chronic stress in asthma attacks in children. Lancet, 356, 982–987. doi: http://dx.doi.org/10.1016/s0140-6736(00)02715-x

Sandelowski, M. (2000). Focus on research methods: What ever happened to qualitative description? *Research in Nursing & Health, 23,* 334-340. doi: http://dx.doi.org/10.1002/1098-240x(200008)23:4%3C334::aid-nur9%3E3.0.co;2-g

Sanders, V.M., Kasprowicz, D.J., Kohm, A.P. & Swanson, M.A. In Ader, R., Felten, D. L. & Cohen (Eds.), *Psychoneuroimmunology* 3rd ed., Vol. 1, 132–15. Academic: San Diego.

Schaefer, J. (2010). *Theology 6995 Independent Study in Adolescent Spirituality and Religiosity,* Personal discussion with Jame Schaefer, PhD, Director, Marquette University, Milwaukee, Wisconsin.

Sessana, L., Finnell, D., & Jezewski, M.A. (2007). Spirituality in nursing and health -related literature: A concept analysis. *Journal of Holistic Nursing, 25,* 252. doi: http://dx.doi.org/10.1177/0898010107303890

Schwadel, P. (2008). Poor teenagers' religion. *Sociology of Religion, 69* (2), 125-149. doi: http://dx.doi.org/10.1093/socrel/69.2.125

Schwartz, K. D., Murkowski, W. M., & Aoki, W. T. (2006). Mentors, friends, and gurus: Peer and nonparent influences on spiritual development. In E. C. Roehlkepartain, P. E. King, L. M. Wagener, & P. L. Benson (Eds.), *The handbook of spiritual development in childhood and adolescence* (pp. 310–323). Thousand Oaks, CA: Sage.

Schulz, E. (2005). The meaning of spirituality for individuals with disabilities. *Disability and Rehabilitation, 27*(21), 1283-1295. doi: http://dx.doi.org/10.1080/09638280500076319

Serjeant, G.R., Serjeant, I.E. (2001). Sickle Cell Disease (3rd ed.). Oxford University
        Press: Oxford, NY.

Sibinga, E.M., Shindell, D.L., Casella, J.F., Duggan, A.K. & Wilson, M.H. (2006).
        Pediatric patients with sickle cell disease: Use of complementary and alternative
        therapies. *Journal of Complementary and Alternative Medicine, 12* (3), 291-298.
        doi: http://dx.doi.org/10.1089/acm.2006.12.291

Sickle Cell Disease Association Illinois. Retrieved January 13, 2010,
        http://www.sicklecelldisease-illinois.org

Singe, E., Shinwell, D., Casella, J., Duggan, A., & Wilson, M.H. (2006). Pediatric
         patients with sickle cell disease: Use of complementary and alternative therapies.
        The Journal of Alternative and Complimentary Medicine, 12(3), 291-298.

Smith, C. & Lundquist-Denton, M. (2005). *Soul searching: The religious and spiritual
        lives of American teenagers.* Oxford, NY: Oxford University Press.

Smith, L.A., Oyeku, S.O., Homer, C. & Zuckerman, B. (2004). Sickle cell disease: A
        question of equity. *Pediatrics, 117,* 1763-1770.
        doi: http://dx.doi.org/10.1542/peds.2005-1611

Smith, J. & McSherry, W. (2004). Spirituality and child development: A concept
        analysis. *Journal of Advanced Nursing, 45*(3), 307-315.
        doi: http://dx.doi.org/10.1046/j.1365-2648.2003.02891.x

Snethen, J.A., Broome, M.E., Kelber, S., & Warady, B. (2004). Coping strategies utilized
        by adolescents with end stage renal disease. *Nephrology Nursing Journal, 31*(1),
        41-9.

Sroufe, A.L. (1997). Psychopathology as an outcome of development. *Development and
        Psychopathology, 9,* 251–268.
        doi: http://dx.doi.org/10.1017/s0954579497002046

Steiner, C.A & Miller, J.L. (2006). *Sickle cell disease patients in U.S. hospitals, 2004*
        (Statistical *brief* #21). Retrieved from
        http://www.hcup-us.ahrq.gov/reports/statbriefs/sb21.pdf

Suris, J.C., Michaud, P.A., & Viner, R. (2004). The adolescent with a chronic condition. Part I: developmental issues. *Archives of Disease in Childhood, 89*, 938-942. doi: http://dx.doi.org/10.1136/adc.2003.045369

Tanyi, R. (2002). Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing, 39* (5), 500-509. doi: http://dx.doi.org/10.1046/j.1365-2648.2002.02315.x

Tartaro, J., Luecken, L.J., & Gunn, H.E. (2005). Exploring heart and soul: Effects of religiosity/spirituality and gender on blood pressure and cortisol stress responses. *Journal of Health Psychology, 10* (6), 753-766. doi: http://dx.doi.org/10.1177/1359105305057311

Taylor, E.J. (2002). *Spiritual care: Nursing care: Nursing theory, research, and practice.* Upper Saddle River, NJ: Prentice Hall.

Taylor, R.J., Mattis, J., & Chatters, L.M. (1999). Subjective religiosity among African Americans: A synthesis of findings from five national samples. *Journal of Black Psychology, 25, 524-543.* doi: http://dx.doi.org/10.1177/0095798499025004004

Trinitapoli, J. (2007). Religious exclusivism among US adolescents. *The Sociological Quarterly, 48*, 451-483. doi: http://dx.doi.org/10.1111/j.1533-8525.2007.00085.x

Trousdale, Bach, & Willis (2010). Freedom, physicality, friendship and feeling: aspects of children's spirituality expressed through the choral reading of poetry. *International Journal of Children's Spirituality, 15*(4), 317. doi: http://dx.doi.org/10.1080/1364436x.2010.529874

Uchendu, U.O., Ikefuna, A.N., Nwokocha, A.R., & Emodi, I.J. (2010). Impact of socioeconomic status on sexual maturation of Nigerian boys living with sickle cell anemia. *Hematology, 15* (6), 414-421. doi: http://dx.doi.org/10.1179/102453310x12647083621209

Umlauf, M.G. (1997). *Healing meditation.* Albany, NY: Delmar.

U.S. Census Bureau, Current Population Survey, 2013 Annual Social and Economic Supplement. Retrieved January 28, 2014, from http://www.census.gov/hhes

U.S Census Bureau, 2012 American Community Survey 1-Year Estimates, Retrieved via American FactFinder January 28, 2014, from http://www.factfinder2.census.gov

U.S. Department of Health and Human Services. (n.d.). Healthy people. Retrieved April 1, 2010, from http://www.healthypeople.gov/hp2020/Objectives

U.S. Department of Health and Human Services. National Institute of Health. National Heart, Lung, and Blood Institute (2011). Health Topics. Retrieved November 10, 2011, from http://www.nhlbi.nih.gov/health/health-topics/topics/sca

U.S. Department of Health and Human Service. National Institute of Health. National Heart, Lung, and Blood Health Institute (2002). Retrieved November 30, 2011 from http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf

Varghese, S. (2008). The lived experience of adolescents with sickle cell disease. *Southern Online Journal of Nursing Research, 8(2),* 2p.

Veenhoven R. Sociological theories of subjective well-being (2008). In: Eid, M., Larsen, R.J. (eds). *The science of subjective well-being*. New York: Guilford Press; 44–61

Verduzco, L.A. & Nathan, D.G. (2009). Sickle cell disease and stroke. *Blood, 114* (25), 5117-5125.
doi: http://dx.doi.org/10.1182/blood-2009-05-220921

Walker, S. (2005). Towards culturally competent practice in child and adolescent mental health. *International Social Work, 48* (1), 49-62.
doi: http://dx.doi.org/10.1177/0020872805048708

Wang, W.C., Ware, R.E., Miller, S.T., Iyer, R.V., Casella, J.F., Minniti, C.P., Rana, S., Thornburg, C.D., Rogers, Z.R., Kalpatthi, R.V., Barredo, J.C., Brown, R.C., Sarnaik, S.A., Howard, T.H., Wynn, L.W., Kutlar, A., Armstrong, F.D., Files, B.A., Goldsmith, J.C., Waclawiw, M.A., Huang, X., & Thompson, B.W. (2011). Hydroxycarbamide in very young children with sickle cell anemia: A multicentre, randomised, controlled trial (BABY HUG). *The Lancet, 377,* 1663-1672. doi: http://dx.doi.org/10.1016/s0140-6736(11)60355-3

Watson, J. (2012). *Human caring science: a theory of nursing.* Sudbury, MA: Jones & Bartlett Learning.

Weinblatt, M.E. (1998). Sickle Cell Disease. In Friedmann, S.B., Fisher, M., Schonberg, S.K., & Alderman, E.M. (Eds.), *Comprehensive adolescent health care*. St. Louis: Mosby.

While, A.E. (2004). Living with sickle cell disease: the perspective of young people. *British Journal of Nursing, 13*(6), 320-325.

Wilson, M. & Nicholson, K. (2008). Spiritual development with marginalized youth: A status report. *New Directions for Youth Development, 118, 115-118.* doi: http://dx.doi.org/10.1002/yd.265

Wison-Schaeffer, J. J., Gil, K., M., Burchinal, M., Kramer, K. D., Nash, K.B., Orringer, E., & Strayhorn, D. (1999). Depression, disease severity, and sickle cell disease. *Journal of Behavioral Medicine, 22,*115-126.

Woodgate, R.L. & Degner, L.F. (2003). A substantive theory of keeping the spirit alive: the spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing, 20* (3), 103-119. doi: http://dx.doi.org/10.1053/jpon.2003.75

Woods, K.F. & Ballas, S.K. (2006). Sickle Cell Disease and Hemoglobinopathies. In Satcher, D. & Pammies, R.J. (Eds.), *Multicultural medicine and health disparities.* New York: McGraw-Hill.

World Health Organization. (2011). *Sickle cell disease and other haemoglobin disorders.* Retrieved from http://www.who.int/ mediacentre/factsheets/ fs308/en/.

World Health Organization. (2006). *Sickle-cell anemia* (WHO Executive Board Report, Report of the Secretariat, EB 117/R3). Retrieved from http://www.who.int/nmh /eb117/ en/ index2.html.

Yoon, S.L., & Black, S. (2006). Comprehensive, integrative management of pain for patients with sickle-cell disease. *The Journal of Alternative and Complementary Medicine, 12*(10), 995-1001.
doi: http://dx.doi.org/10.1089/acm.2006.12.995

Young, C. & Koopsen, C. (2010). Spirituality, health, and healing. Sudbury, MA; Jones and Bartlett.

Zebrack, B.J., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K.A., Li, Y., Butler, M., and Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer, 119* (1), 201-214.
doi: http://dx.doi.org/10.1002/cncr.27713

APPENDICES

APPENDIX A

Dear Teenager,

My name is Dora Jones; I am a registered nurse (RN). I would like to talk with you about

a study that I will be doing with teenagers who have sickle cell disease. I would like to

learn what is important to you, how do you describe your spiritual and religious beliefs,

your thoughts on your beliefs, and how do your beliefs fit into your life. I believe that the

information you give will help health providers caring for teenagers with sickle cell

disease.

If you decide to be in the study I will interview twice by asking you questions. You will

receive a $25 Visa gift card after completing each interview. Each interview lasts no

more than one hour. Interviews will take place at Children's Memorial Hospital and

SCDAI.

I would like to give you more information about this study. If you want to know more

about it before you leave today, please tell your facilitator and I will talk with you today.

If you want to know more about the study but would like to speak with me at another

time, you may call me in Wisconsin at 414-219-9080.

Sincerely,

Dora Clayton-Jones

APPENDIX B

Dear Parent,

My name is Dora Clayton-Jones; I am a registered nurse (RN). I would like to talk with your child about a study that I will be doing with teenagers who have sickle cell disease. I would like to learn what is important to your child, learn more about your child's thoughts on their spiritual and religious beliefs, and how do your child's beliefs fit into their life. I believe that the information your child gives will help health providers caring for teenagers with sickle cell disease.

If you as a parent decide to allow your child to participate in the study, I will interview your child twice by asking your child questions. There are a total of two interviews. Your child will receive a $25 Visa gift card after completing each interview. Each interview lasts no more than one hour.

I would like to give you more information about this study. If you want to know more about it before you leave today, please tell your facilitator and I will talk with you today. If you want to know more about the study but would like to speak with me at another time, you may call me in Wisconsin at 414-219-9080.

Sincerely,

Dora Clayton-Jones

APPENDIX C

Protocol Number: _____

MARQUETTE UNIVERSITY
STATEMENT OF
PARENT CONSENT FORM FOR STUDY

Consent for: Spirituality and religiosity in Adolescents with Sickle Cell Disease

Investigator(s): Dora Jones, RN, MSN   **Phone Number:** 414-219-9080

MEDICAL OR OTHER LANGUAGE CAN BE CONFUSING. IF THERE IS ANYTHING THAT YOU DO NOT UNDERSTAND, PLEASE ASK QUESTIONS.
What is the Problem? We know little about how teens living with sickle cell disease use religion and spirituality at any time during their life.

 What is the Purpose? We are doing a research study. A research study is a special way to find out about something. We want to find out your child's experience with religion or what gives you meaning in living with sickle cell disease.

What is to be Done? Your child will be allowed to participate in this study if you agree. If you want your child to be in this study, your child will be asked to complete one survey and two interviews in two separate meetings. Your child will be asked questions about themselves, their religion, and their health. Other teens will be included in this study. All of your child's answers to the questions in the interview will be audio recorded and then later transcribed (put down in writing on paper). This will be done in a private way so that no one, including any of the doctors or nurses who take care of your child, will be able to match your child to his/her answers. We will take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience religion and spirituality and how important those practices are to them. We will keep the actual audio recording of your child's answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and de-identified data will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research. About 10 other teens are needed to participate in this study. We want to hear from teens themselves. Your child will be given a $25 Visa gift card for participating in this study after completing the survey and first interview. Your child will be given a $25 Visa gift card if your child completes the second interview. Your child will be asked to sign a receipt for the payment. Each interview lasts approximately one hour. You and your child will be asked questions providing demographics and personal information about you and your family.

What are the Risks? There are no known risks to your child from being in this study. We may ask some questions that your child may be uneasy answering. Your child is free

not to answer. If you feel like you would like your child to talk with someone after the study is complete, please contact your support group organization.

What are the Possible Benefits? If you agree for your child to be in this study, some good things might happen. Your child will help us learn more about teens that may be used to help other teens some day.

Do you have to participate in this Study?
Even if you agree for your child to participate in this study, it is still your decision whether or not to be in the study. It is also your decision to answer questions about you and your family. You do not have to be in this study if you don't want to. You can say "no" and nothing bad will happen. Your child's care in this organization now or in the future will not be affected in any way if you agree for your child to participate. If you say "yes" now, but you or your child want to stop later, that's okay too. If something about the study bothers you or your child, you can stop your child from being in the study and your child can stop from being in this study. All you or your child would have to do is tell the researcher you or your child wants to stop.   The information your child gives up to that point will be used in the study unless you or your child asks us to remove it. If there is anything you or your child doesn't like about being in the study, you or your child should tell us. If we can, we will try to change it for you or your child.

Questions? If you have more questions please call Dora Jones at 414-219-9080 or my faculty advisor Dr. Kristin Haglund at 414-288-3824. We will try to explain everything that is being done and why. Please ask us about anything you or your child want to know. Once this study is done, we would be happy to share the results with you or your child. This research project has been approved by special committees. The committees see that the rights and safety of patients are protected. A member of one of these committees is available to speak to you or your child if either you have any questions. The research project has also been approved by the Marquette University Institutional Review Board for the Protection of Human Subjects for a one year period. If you or your child have any concerns about treatment while participating in this study, please contact Marquette University Office of Research Compliance, Schroeder Complex, 102, 560 N. 16th Street, P.O. Box 1881, Milwaukee, WI 53201-1881, PH: 414-288-7570.
.

Will Information be Confidential?
When we are done with the study, we will write a report about what we find. All the information your child gives will be kept private. No one except the research team will know that your child is in the study unless you or your child decides to tell them. The only time that we would break this rule is if your child tells us information you need to know. This would be to keep your child or others safe. For example, if your child has had thoughts about hurting herself/himself in some way, we would tell you as the parent. If your child tells us that he or she has been abused and this has not been reported, we will have to report it to Child Protection Services (CPS). You and your child will be told

ahead of time if we make a report to CPS. Information from this study may be shared at meetings or printed. It may be useful to others, but it will not identify your child. Each participant will be given an identification number that will be used on all data. All data will be stored in a locked file and only the researcher will be able to open and read the data. After the study is done, the main list of names and identification numbers will be destroyed. Receipts will be turned in to Marquette or be destroyed. Consents and surveys will be destroyed 5 years after the study is done. No report will contain identifying information.

Consent to Proceed

If you want your teen to be in this study, please sign and print your name.

_____   _____
Parent (Print Name)   (Date)

_____   _____
Parent signature   (Date)

This study explained was to me. I agree for my teen to participate in this study. I understand that my teen's   participation in this study is voluntary.

APPENDIX D

Protocol Number: _____

MARQUETTE UNIVERSITY
STATEMENT OF
VOLUNTEER ASSENT FORM FOR STUDY

Consent for: Spirituality and religiosity in Adolescents with Sickle Cell Disease

Investigator(s): Dora Jones, RN, MSN   **Phone Number:** 414-219-9080

MEDICAL OR OTHER LANGUAGE CAN BE CONFUSING. IF THERE IS ANYTHING THAT YOU DO NOT UNDERSTAND, PLEASE ASK QUESTIONS.
What is the Problem? We know little about how teens living with sickle cell disease use religion at any time during their life.

What is the Purpose? We are doing a research study. A research study is a special way to find out about something. We want to find out your experience with religion or what gives you meaning in living with sickle cell disease.

What is to be Done? You can be in this study if you want to. If you want to be in this study, you will be asked to complete one survey and two interviews in two separate meetings. You will be asked questions about yourself, your religion, and your health. All of your answers to the questions in the interview will be audio recorded and then later transcribed (put down in writing on paper). This will be done in a private way so that no one, including any of the doctors or nurses who take care of you, will be able to match you to your answers. We will take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience religion and spirituality and how important those practices are to them. We will keep the actual audio recording of your answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and data that will not identify you will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research. About 10 other teens are needed to participate in this study. We want to hear from teens themselves. You will be given a $25 Visa gift card for participating in this study if you complete the survey and first interview. You will be given a $25 Visa gift card if you complete the second interview. You will be asked to sign a receipt for the payment. Each interview lasts approximately one hour. You will also be asked questions providing demographics and personal information about you and your family.

What are the Risks? There are no known risks to you from being in this study. We may ask some questions that you may be uneasy answering. You are free not to answer. If you feel like you would like to talk with someone after the study is complete, please contact your support group organization.

What are the Possible Benefits? If you decide to be in this study, some good things might happen. You will help us learn more about teens that may be used to help other teens some day.

Do you have to participate in this Study?
Even if your parent/guardian agrees for you to participate in this study, it is still your decision whether or not to be in the study. You do not have to be in this study if you don't want to. You can say "no" and nothing bad will happen. Your health care in this clinic now or in the future will not be affected in any way if you choose to participate. If you say "yes" now, but you want to stop later, that's okay too. If something about the study bothers you, you can stop being in the study. All you have to do is tell the researcher you want to stop. The information you give up to that point will be used in the study unless you ask us to remove it. If there is anything you don't like about being in the study, you should tell us. If we can, we will try to change it for you.

Questions? If you have more questions please call Dora Jones at 414-219-9080 or my faculty advisor Dr. Kristin Haglund at 414-288-3824. We will try to explain everything that is being done and why. Please ask us about anything you want to know. Once this study is done, we would be happy to share the results with you. This research project has been approved by special committees. The committees see that the rights and safety of patients are protected. A member of one of these committees is available to speak to you if you have any questions. The research project has also been approved by the Marquette University Institutional Review Board for the Protection of Human Subjects for a one year period. If you have any concerns about your treatment while participating in this study, please contact Marquette University Office of Research Compliance, Schroeder Complex, 102, 560 N. 16th Street, P.O. Box 1881, Milwaukee, WI 53201-1881, PH: 414-288-7570.

Will Information be Confidential?
When we are done with the study, we will write a report about what we find. All the information you give will be kept private. No one except the research team will know that you are in the study unless you or your parents decide to tell them. The only time that we would break this rule is if you tell us information we think your parents need to know. This would be to keep you or others safe. For example, if you have been having thoughts about hurting yourself in some way, we would tell your parents. If you tell us that you have been abused and this has not been reported, we will have to report it to Child Protection Services (CPS). You will be told ahead of time if we make a report to CPS. Information from this study may be shared at meetings or printed. It may be useful to others, but it will not identify you. Each participant will be given an identification number that will be used on all data. All data will be stored in a locked file and only the

researcher will be able to open and read the data. After the study is done, the main list of names and identification numbers will be destroyed. Receipts will be turned in to Marquette or be destroyed. Consents and surveys will be destroyed 5 years after the study is done. No report will contain identifying information.

Permission to Proceed: Signing this form will not affect your care in this clinic or project. I understand what will happen if I participate in this study. It has been explained to me by:

Investigator   Dora Jones, CPNP_____
                 Print Name of Principal Investigator or Authorized Person

                 _____   _____
                 Signature of Principal Investigator or Authorized Person   Date

If you want to be in this study, please sign and print your name.

I, _____, want to be in this research study.
                 (Write your name here)

_____   _____
Sign your name here   (Date)

"This study explained was to me. I agree to participate in this study. I understand that my participation in this study is voluntary.

APPENDIX E

Protocol Number: _____

MARQUETTE UNIVERSITY
STATEMENT OF
ADULT CONSENT FORM FOR STUDY

Consent for: Spirituality and religiosity in Adolescents with Sickle Cell Disease

Investigator(s): Dora Jones, RN, MSN   **Phone Number:** 414-219-9080

MEDICAL OR OTHER LANGUAGE CAN BE CONFUSING. IF THERE IS ANYTHING THAT YOU DO NOT UNDERSTAND, PLEASE ASK QUESTIONS.
What is the Problem? We know little about how teens living with sickle cell disease use religion at any time during their life.

 What is the Purpose? We are doing a research study. A research study is a special way to find out about something. We want to find out your experience with religion or what gives you meaning in living with sickle cell disease.

What is to be Done? You can be in this study if you want to. If you want to be in this study, you will be asked to complete one survey and two interviews in two separate meetings. You will be asked questions about yourself, your religion, and your health. All of your answers to the questions in the interview will be audio recorded and then later transcribed (put down in writing on paper). This will be done in a private way so that no one, including any of the doctors or nurses who take care of you, will be able to match you to your answers. We will take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience religion and spirituality and how important those practices are to them. We will keep the actual audio recording of your answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and de-identified data will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research. About 10 other teens are needed to participate in this study. We want to hear from teens themselves. You will be given a $25 Visa gift card for participating in this study if you complete the survey and first interview. You will be given a $25 Visa gift card if you complete the second interview. You will be asked to sign a receipt for the payment. Each interview lasts approximately one hour. You will also be asked questions providing demographics and personal information about you and your family.

What are the Risks? There are no known risks to you from being in this study. We may ask some questions that you may be uneasy answering. You are free not to answer. If you feel like you would like to talk with someone after the study is complete, please contact your support group organization.

What are the Possible Benefits? If you decide to be in this study, some good things might happen. You will help us learn more about teens that may be used to help other teens some day.

Do you have to participate in this Study?

You do not have to be in this study if you don't want to. You can say "no" and nothing bad will happen. Your health care in this clinic now or in the future will not be affected in any way if you choose to participate. If you say "yes" now, but you want to stop later, that's okay too. If something about the study bothers you, you can stop being in the study. All you have to do is tell the researcher you want to stop. The information you give up to that point will be used in the study unless you ask us to remove it. If there is anything you don't like about being in the study, you should tell us. If we can, we will try to change it for you.

Questions? If you have more questions please call Dora Jones at 414-219-9080 or my faculty advisor Dr. Kristin Haglund at 414-288-3824. We will try to explain everything that is being done and why. Please ask us about anything you want to know. Once this study is done, we would be happy to share the results with you. This research project has been approved by special committees. The committees see that the rights and safety of patients are protected. A member of one of these committees is available to speak to you if you have any questions. The research project has also been approved by the Marquette University Institutional Review Board for the Protection of Human Subjects for a one year period. If you have any concerns about your treatment while participating in this study, please contact Marquette University Office of Research Compliance, Schroeder Complex, 102, 560 N. 16th Street, P.O. Box 1881, Milwaukee, WI 53201-1881,
PH: 414-288-7570.
.

Will Information be Confidential?

When we are done with the study, we will write a report about what we find. All the information you give will be kept private. No one except the research team will know that you are in the study unless you decide to tell them. This would be to keep you or others safe. Information from this study may be shared at meetings or printed. It may be useful to others, but it will not identify you. Each participant will be given an identification number that will be used on all data. All data will be stored in a locked file and only the researcher will be able to open and read the data. After the study is done, the main list of names and identification numbers will be destroyed. Receipts will be turned in to Marquette or be destroyed. Consents and surveys will be destroyed 5 years after the study is done. No report will contain identifying information.

Permission to Proceed: Signing this form will not affect your care in this clinic or project. I understand what will happen if I participate in this study. It has been explained to me by:

Investigator   Dora Jones, CPNP_____

　　　　　　　　　　Print Name of Principal Investigator or Authorized Person

　　　　　　　　　　_____   _____

　　　　　　　　　　Signature of Principal Investigator or Authorized Person　　　Date

If you want to be in this study, please sign and print your name.

I, _____, want to be in this research study.

　　　　　　　(Write your name here)

_____　　　　_____

Sign your name here　　　　　　　　　　　　　　　　(Date)

"This study explained was to me. I agree to participate in this study. I understand that my participation in this study is voluntary.

APPENDIX F

Protocol Number: _____

CHILDREN'S MEMORIAL HOSPITAL
INSTITUTIONAL REVIEW BOARD

Permission for a Child to Participate in a Research Project

Investigators at Children's Memorial Hospital invite you to consider having your child participate in a research study entitled:

Spirituality and religiosity in Adolescents with Sickle Cell Disease: A Qualitative Study
Sponsored by: Dora Jones, MSN, RN, CPNP, Marquette University and carried out by Alexis Thompson, MD.

WHY IS THIS STUDY BEING DONE?

Sickle Cell Disease (SCD) is a chronic condition that can affect a person's health and wellbeing in many different ways. The most common problems SCD patients experience are pain, acute chest, splenic sequestration, and stroke.

Adolescents with SCD cope with their disease in many different ways. In addition to medical care, supportive and self-care practices may help adolescents manage their illness and avoid some of the problems SCD may cause. Supportive and self-care practices include support groups, reaching out to friends and community, and religious beliefs and practices (what we call spirituality and religiosity).

Spirituality and religiosity are experienced differently for different people. Spirituality and religiosity can influence patients' beliefs about their health, healthcare choices, and self-care practices.

We want to find out what spirituality and religiosity mean to teenagers with SCD. We also want to find out how teenagers with SCD experience spirituality and religiosity in their personal lives. Lastly, we want to find out what role spirituality and religiosity has in their beliefs about health and illness.

Your child qualifies for this study because your child has been diagnosed with SCD and is between the ages of 12 and 17. About 10 other teenagers with SCD will be participating in this study from Children's Memorial Hospital (CMH) and the Sickle Cell Disease Association of Illinois (SCDAI).

WHAT IS INVOLVED IN THE STUDY AND HOW LONG WILL MY CHILD BE IN THE STUDY?

If you agree to allow your child to participate in this study, your child will take part in 2, 1-on-1, semi-structured interviews with a member of our research team who is not

directly involved in your child's care. You and your child will each first be asked to fill out a short survey that will tell us a little more about you and your child. Your child will then be asked about 12 questions during each interview. There are no right or wrong answers to the questions. We are interested in hearing your opinion about things like:

- What things are important to your child
- What your child thinks about his or her religious and spiritual beliefs
- How do your religious and spiritual beliefs fit into your child's life

There will be 2 interviews on 2 separate days. Each interview should last no longer than 1 hour.

All of your child's answers to the questions in the interview will be digitally recorded and then later transcribed (put down in writing on paper). This will be done in a confidential (private) way so that no one, including any of the doctors or nurses who take care of your child, will be able to match your child to your child's specific answers. We will then take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience spirituality and religiosity and how important those practices are to them. We will keep the actual audio recording of your answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and de-identified data will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research.

ARE THERE BENEFITS (GOOD THINGS) TO TAKING PART IN THE STUDY?

There are no direct benefits to you or your child for having your child participate in this study. However, your child's participation may help us learn more about how teens with SCD describe and experience spirituality and religiosity. Finally, it may give healthcare providers additional resources to help patients cope with SCD.

WHAT ARE THE POSSIBLE RISKS OR SIDE EFFECTS (BAD THINGS) OF THE STUDY?

It is unlikely that your child will experience any side effects from participating in this study. However, there are people who may find some of the questions emotionally upsetting because they deal with hard things to talk about. Your child does not have to answer any questions that make your child feel uncomfortable.

WHAT OTHER OPTIONS ARE THERE?

Your child does not have to participate in this study. You may cancel your consent and withdraw your child from this study at any time. You and your child will not be penalized if you withdraw your child from this study. If you withdraw your child from this study, he or she will receive the usual treatment for SCD which his or her doctor would

prescribe.

WHAT ARE THE COSTS?

There are no costs associated with having your child participate in this study.

WILL I BE TOLD ABOUT NEW INFORMATION?

Although it is unlikely to be the case, we will tell you if we learn new information that may make you change your mind about your child being in this study.

WILL THERE BE COMPENSATION FOR MY CHILD'S PARTICIPATION?

After you and your child complete the surveys and your child completes the first interview, you will receive a $25 gift card to compensate you for your child's participation in the study. You will receive an additional $25 gift card after your child completes the second interview. The gift cards will be given to you by a member of the study staff. You will be asked to sign a receipt for the payment.

If your child does not complete the study, you will only be compensated for the interviews your child completes with a gift card of $25/interview.

WHAT DO I DO IF MY CHILD IS INJURED?

If your child is injured, medical facilities and treatment will be available. However, you will be required to pay a reasonable fee for such care. Your child can still receive medical benefits if otherwise entitled. If you have any questions or desire further information concerning the availability of medical care, you may contact Dr. Edward Ogata, Chief Medical Officer, The Children's Memorial Hospital, 2300 Children's Plaza, no. 2, Chicago, Illinois, 60614-3363 [773/868-8056].

WHO WILL KNOW ABOUT WHAT MY CHILD DID IN THE STUDY OR HAVE ACCESS TO MY CHILD'S PRIVATE INFORMATION?

This signed consent form will be placed in your child's medical record at Children's Memorial Hospital with a copy placed in the Principal Investigator's research file. Some or all of the research results may be included in your child's medical records. If your child does not have a medical record at Children's Memorial Hospital, then this signed consent form will only be kept in the Principal Investigator's research file.

The principal investigator, co-investigators, Children's Memorial Hospital doctors who are involved in the study and the staff who work on the study, such as study nurses and coordinators, will have access to your child's personal health and medical information, and study results. Children's Memorial Hospital Institutional Review Board, the committee that is in charge of protecting the rights of all adults and children who participate in research studies at Children's Memorial Hospital, may also have access to this information. They are required to keep your personal information confidential.

The records of this study will be kept confidential with respect to any written or oral reports to the profession or the media, making it impossible to identify your child individually.

WHAT ARE MY CHILD'S RIGHTS AS A PARTICIPANT?

By signing this consent form, you agree to have your child take part in this study. You are not giving up any of your or your child's legal rights or releasing this hospital from responsibility for carelessness.

You may cancel your consent and take your child out of this study at any time. Neither you nor your child will be penalized for doing this. Your child's treatment by, and relations with the physician(s) and staff at Children's Memorial Hospital, now and in the future, will not be affected in any way if you do not want your child to take part in this study, or if you enter your child into the study and then withdraw your child from it.

At any time, you can tell your child's doctor or Children's Memorial Hospital not to use or give out your child's study information. Withdrawal of this permission must be in writing. Any study information or other information from your child's medical record collected before your written notice of permission withdrawal may still be used for the study, if that information is necessary for the study. Your decision will not affect your child's regular care and your child's doctor will not change his or her feelings about you.

If you agree to let your child take part in this research study, you will not be able to look at or ask for a copy of your child's health information collected only for this study, while your child is taking part in the study. If you wish, you will be able to ask for this study research information when the study is over or when your child is no longer taking part in the study. This does not affect your right to see your child's medical record or the results of tests related to regular medical care that is given during the same time as the research study.

If you have or your child has any questions about the research methods, you should contact Dr. Alexis Thompson by contacting her at 773-880-4562 during a workday or 773-880-4000 at night or on weekends. You can also contact Dora Clayton-Jones by calling 414-219-9080.

If you have any questions about your child's rights as a research subject, you may take them to Philip V. Spina, Sr. Vice-President and Chief Operating Officer, Children's Memorial Research Center, 2300 Children's Plaza, no. 205, Chicago, Illinois 60614-3363. [Ph: 773/755-6301, Fax: 773/755-6533, Email: pspina@childrensmemorial.org]. You may also contact Marquette University Office of Research Compliance, Schroeder Complex, 102, 560 N. 16th Street, P.O. Box 1881, Milwaukee, WI 53201-1881, [PH 414-288-7570]. You will be given a signed and dated copy of this consent form.

SIGNATURES

I agree to let my child's doctor or Children's Memorial Hospital use and give out my child's health information in the way it is described in this consent form until the end of the research study.

I have read this consent form, and I agree to have my child, _____ (clearly write the child's name) take part in this study as explained in this consent form.

Date	Signature of Parent(s) or Surrogate(s)

Identify the signatory: e.g. Parent, Guardian,

I certify that I have explained the above to the parent(s) and/or surrogate(s) and believe that the signature(s) was affixed freely. I also agree to answer any questions that may arise.

Date	Signature of Person Obtaining Consent

Printed Name of Person Obtaining Consent

Date	Signature of Principal Investigator (if not listed above)

Printed Name of Interpreter: _____

Printed Name of Witness: _____

Signature of Witness: _____

APPENDIX G

Protocol Number: _____

CHILDREN'S MEMORIAL HOSPITAL
INSTITUTIONAL REVIEW BOARD

Adolescent's Agreement to Participate in a Research Study
Ages 12- 17

We are asking you to be in a research study called:

Spirituality and religiosity in Adolescents with Sickle Cell Disease: A Qualitative Study

The study is being done by Alexis Thompson, MD at Children's Memorial Hospital and Dora Jones RN, MSN, CPNP from Marquette University in Milwaukee Wisconsin.
.

WHY IS THIS STUDY BEING DONE?

We want to tell you about a research study at Children's Memorial Hospital. Research studies help us find better ways to take care and treat children who are sick with a disease, to learn how medicines work, and how our bodies work. Research studies are voluntary, which means that you only have to participate in the study if you want.

We are asking you to be in this research study because you have Sickle Cell Disease.

We are asking you to be in this research study because we want to hear about:
- What things are important to you
- Your thoughts about religious and spiritual beliefs
- How do your religious and spiritual beliefs fit into your life

WHAT HAPPENS IN THE STUDY AND HOW LONG WILL I BE IN THE STUDY?

If you want to be in the study, this is what will happen:
- You will first answer questions on a sheet of paper to tell us more about yourself
- You will be asked questions, or "interviewed," by one of the study staff members. You will be interviewed 2 times. Each time will take 1 hour. You will be asked about 12 questions in each interview. We will ask you about what is important to you and how religious and spiritual beliefs fit into your life.
- All of your answers to the questions in the interview will be audio recorded and then later transcribed (put down in writing on paper). This will be done in a

private way so that no one, including any of the doctors or nurses who take care of you, will be able to match you to your answers. We will take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience religion and spirituality and how important those practices are to them. We will keep the actual audio recording of your answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and information that will not identify you will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research. About 10 other teens are needed to participate in this study.

WHAT ARE THE GOOD THINGS ABOUT THE STUDY?

Although you will not benefit directly from this study, we hope to learn something that could help other children in the future who have sickle cell disease.

WHAT ARE THE NOT-SO-GOOD, BAD, OR HARMFUL THINGS THAT COULD HAPPEN TO ME IF I AGREE TO BE IN THIS STUDY?

The questions we ask you as part of the study might seem strange and maybe make you

feel sad or embarrassed. If you don't want to, you don't have to answer these questions.

We will tell you if we learn new information that may make you change your mind about being in this study.

WHAT OTHER OPTIONS ARE THERE?

You do not have to be in this study if you don't want to. If you join the study and then change your mind, it is okay for you to leave this study. Your will not be upset with you if you do.

WHAT ABOUT MY CONFIDENTIALITY?

We will do everything possible to make sure that your medical records are kept private. Some or all of the research results may be included in your medical records.

Unless required by law, only representatives of the following groups or organizations can review your study records.
- Dora Jones, MSN, RN, CPNP
- The Children's Memorial Hospital Institutional Review Board (IRB): This is the hospital's board that is in charge of protecting the rights of all adults and children who participate in research studies.

- The Marquette University Office of Research Compliance
- Government agencies with responsibilities to oversee research studies.

They are required to keep your personal information private.

WILL I RECEIVE ANYTHING IF I AM IN THIS STUDY?

You will be given a $25 Visa gift card for completing the survey and 1st interview. You will be given another $25 Visa gift card for completing the 2nd interview.

WHAT IF I HAVE QUESTIONS?

You can ask questions whenever you have them. You can ask your doctor, nurse or other people working with them on the study, like Dr. Alexis Thompson, by contacting her at 773-880-4562, or athompson@childrensmemorial.org during the workday or 773-880-4000 at night or on weekends. You can also contact Dora Clayton-Jones by calling 414-219-9080. You can also ask your parents.

Your parents know about the study and said that it is okay if you want to be in the study. If you don't want to be in the study, that is okay.

You can ask Dr. Alexis Thompson anything about the study. If you are not happy with this study and want to talk with someone else, not the doctor or the people working with the doctor, you may contact Philip V. Spina, Senior Vice-President and Chief Operating Officer at Children's Memorial Research Center, at 773-755-6301 or pspina@childrensmemorial.org. His address is 2300 Children's Plaza, no. 205, Chicago, Illinois 60614-3394.

You will be given a signed and dated copy of this form.

SIGNATURES

I have read this assent form, and I agree to take part in this study as it is explained in this assent form.

_____   _____
       Date   Signature of Child or Adolescent (only 12-17 years old)

                                _____
                                Printed Name of Child/Adolescent

CMH requires that the date and the signature of the person (not necessarily the principal investigator) explaining the study to the subject(s) and parent(s) or surrogate(s) appear on the consent or assent document, and that that date be the same or an earlier date to that of the subject/parents/surrogate. The principal investigator also must sign the consent or assent form, if he/she is not the person explaining the study, but he/she does not necessarily need to do so on the same or prior date. The following paragraph should be used verbatim after the above subject signature:

Please indicate how assent was obtained by initialing the applicable line.

_____ I certify that I have explained the above to this research subject and believe that the signature was affixed freely. I also agree to answer any questions that may arise.

_____ Written assent was not obtainable because _____. However, I certify that I have explained the above to this research subject and believe that verbal assent was freely given. I also agree to answer any questions that may arise.

_____ Verbal assent could not be obtained because _____.
(Contact IRB Chair or his/her designee for approval of a waiver of assent prior to proceeding with research).

_____	_____
Date	Signature of Person Obtaining Consent
	_____
	Printed Name of Person Obtaining Consent
_____	_____
Date	Signature of Principal Investigator (if not listed above)

STOP: *The following signature lines must be completed if you <u>unexpectedly</u> consent a non-English speaking adolescent research subject and there is no IRB approved translation of the English consent form/assent form into a language understandable to the research subject. .   In order to obtain consent, an interpreter must interpret the English assent form for the adolescent research subject **and** the adolescent research subject must sign the IRB approved short form consent document that has been translated into a language understandable to the research subject. ,. Copies of several IRB approved translated short form consents are available on the IRB Website.*

*If the short form is not available in a language understandable to the research subject an interpreter must interpret the English assent form for the adolescent research subject **and** the subject signs the English assent form.*

In addition, the PI must fulfill the IRB requirements regarding parent/guardian consenting.
Please see the IRB Policy and Procedures Manual for the complete policy and specific IRB requirements, including signature requirements, when consenting/assenting non English speaking research subjects.

NOTE: If you anticipate that you will enroll non-English speaking subjects on a regular basis, the IRB-approved English language consent/assent form(s) must be translated and be IRB approved before being presented to subjects.

Printed Name of Interpreter: _____

Note: the interpreter may not be a member of the study team (i.e. listed on the study personnel form) or be related to the research subject.

Printed Name of Witness: _____

Signature of Witness: _____

Note: *The witness should be fluent in both languages and may be the same person as the interpreter.*

APPENDIX H

Protocol Number: _____

CHILDREN'S MEMORIAL HOSPITAL
INSTITUTIONAL REVIEW BOARD

Adult Consent to Participate in a Research Project

Investigators at Children's Memorial Hospital invite you to consider participating in a research study entitled:

Spirituality and religiosity in Adolescents with Sickle Cell Disease: A Qualitative Study

Sponsored by: Dora Jones, MSN, RN, CPNP, Marquette University and carried out by Alexis Thompson, MD.

WHY IS THIS STUDY BEING DONE?

Sickle Cell Disease (SCD) is a chronic condition that can affect a person's health and well-being in many different ways. The most common problems SCD patients experience are pain, acute chest, splenic sequestration, and stroke.

Adolescents with SCD cope with their disease in many different ways. In addition to medical care, supportive and self-care practices may help adolescents manage their illness and avoid some of the problems SCD may cause. Supportive and self-care practices include support groups, reaching out to friends and community, and religious beliefs and practices (what we call spirituality and religiosity).

Spirituality and religiosity are experienced differently for different people. Spirituality and religiosity can influence patients' beliefs about their health, healthcare choices, and self-care practices.

We want to find out what spirituality and religiosity mean to teenagers with SCD. We also want to find out how teenagers experience spirituality and religiosity in their personal lives. Lastly, we want to find out how important religiosity is to teenagers with SCD in managing their condition.

You qualify for this study because you have been diagnosed with SCD and you are between the ages of 18 and 19. About 10 other teenagers with SCD will be participating in this study from Children's Memorial Hospital (CMH) and the Sickle Cell Disease Association of Illinois (SCDAI).

WHAT IS INVOLVED IN THE STUDY AND HOW LONG WILL I BE IN THE STUDY?

If you agree to participate in this study, you will take part in 2, 1-on-1, semi-structured interviews with a member of our research team who is not directly involved in your care. You will first be asked to fill out a short survey that will tell us a little more about you. You will then be asked about 12 questions during each interview. There are no right or wrong answers to the questions. We are interested in hearing your opinion about things like:

- What things are important to you
- What you think about your religious and spiritual beliefs
- How do your religious and spiritual beliefs fit into your life

There will be 2 interviews on 2 separate days. Each interview should last no longer than 1 hour.

All of your answers to the questions in the interview will be digitally recorded and then later transcribed (put down in writing on paper). This will be done in a confidential (private) way so that no one, including and of the doctors or nurses who take care of you, will be able to match you to your specific answers. We will then take everyone's answers and look for patterns in the answers that might help us better understand how teenagers experience spirituality and religiosity and how important those practices are to them. We will keep the actual audio recording of your answers until the study is complete. We will keep the information we learn from the interviews indefinitely. The transcripts and de-identified data will be stored in a password protected file on a private computer indefinitely and may be used for future research or to teach future students about research.

ARE THERE BENEFITS (GOOD THINGS) TO TAKING PART IN THE STUDY?

There are no direct benefits to you for participating in this study. However, your participation may help us learn more about how teens with SCD describe and experience spirituality and religiosity. Finally, it may give healthcare providers additional resources to help patients cope with SCD.

WHAT ARE THE POSSIBLE RISKS OR SIDE EFFECTS (BAD THINGS) OF THE STUDY?

It is unlikely that you will experience any side effects from participating in this study. However, there are people who may find some of the questions emotionally upsetting because they deal with hard things to talk about. You do not have to answer any questions that make you feel uncomfortable.

WHAT OTHER OPTIONS ARE THERE?

You do not have to participate in this study. You may cancel your consent and withdraw from the study at any time. You will not be penalized if you withdraw from this study. If you withdraw from the study, you will receive the usual treatment for SCD which your doctor would prescribe.

WHAT ARE THE COSTS?

There are no costs associated with having your child participate in this study.

WILL I BE TOLD ABOUT NEW INFORMATION?

Although it is unlikely to be the case, we will tell you if we learn new information that may make you change your mind about being in the study.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

After you complete the survey and first interview, you will receive a $25 gift card to compensate you for your participation in the study. You will receive an additional $25 gift card after you complete the second interview. The gift cards will be given to you by a member of the study staff. You will be asked to sign a receipt for the payment.

WHAT DO I DO IF I AM INJURED?

If you are injured, medical facilities and treatment will be available. However, you will be required to pay a reasonable fee for such care. You can still receive medical benefits if otherwise entitled. If you have any questions or desire further information concerning the availability of medical care, you may contact Dr. Edward Ogata, Chief Medical Officer, The Children's Memorial Hospital, 2300 Children's Plaza, no. 2, Chicago, Illinois, 60614-3394 [773/868-8056].

WHO WILL KNOW ABOUT WHAT I DID IN THE STUDY OR HAVE ACCESS TO MY PRIVATE INFORMATION?

This signed consent form will be placed in your medical record at Children's Memorial Hospital with a copy placed in the Principal Investigator's research file. Some or all of the research results may be included in your medical records. If you do not have a medical record at Children's Memorial Hospital, then this signed consent form will only be kept in the Principal Investigator's research file.

The principal investigator, co-investigators, Children's Memorial Hospital doctors who are involved in the study and the staff who work on the study, such as study nurses and coordinators, will have access to your personal health and medical information, and study results. Children's Memorial Hospital Institutional Review Board, the committee that is in charge of protecting the rights of all adults and children who participate in research studies at Children's Memorial Hospital, may also have access to this information. They are required to keep your personal information confidential.

The records of this study will be kept confidential with respect to any written or oral reports to the profession or the media, making it impossible to identify you individually.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

By signing this consent form, you agree to take part in this study. You are not giving up any of your legal rights or releasing this hospital from responsibility for carelessness.

You may cancel your consent and withdraw from this study at any time without penalty or loss of benefits. Your treatment by, and relations with the physician(s) and staff at Children's Memorial Hospital, now and in the future, will not be affected in any way if you refuse to take part, or if you enter into the study and then withdraw from it.

At any time, you can tell your doctor or Children's Memorial Hospital not to use or give out your study information or other information from your medical record to other people or companies. Withdrawal of this permission must be in writing. Any study information or other information from your medical record collected before your written notice of permission withdrawal may still be used for the study, if that information is necessary for the study. Your decision to withdraw from the study will not affect your regular care and your doctor will not change his or her feelings about you.

If you agree to take part in this research study, you will not be able to look at or ask for a copy of your health information collected only for this study, while you are taking part in the study. If you wish, you will be able to ask for this study research information when the study is over or when you are no longer taking part in the study. This does not affect your right to see your medical record or the results of tests related to regular medical care that is given during the same time as the research study.

If you have any questions about the research methods, you should contact Dr. Alexis Thompson by contacting her at 773-880-4562 during a workday or 773-880-4000 at night or on weekends. You can also contact Dora Clayton-Jones by calling 414-219-9080.

If you have any questions about your rights as a participant in a research study (research subject), you may take them to Philip V. Spina, Sr. Vice-President and Chief Operating Office, Children's Memorial Research Center, 2300 Children's Plaza, no. 205, Chicago, Illinois 60614-3363.
[Ph: 773/755-6301, Fax: 773/755-6533, Email: pspina@childrensmemorial.org]. You may also contact Marquette University Office of Research Compliance, Schroeder Complex, 102, 560 N. 16th Street, P.O. Box 1881, Milwaukee, WI 53201-1881, [PH 414-288-7570].

You will be given a signed and dated copy of this consent form.

SIGNATURES

I agree to let my doctor or Children's Memorial Hospital use and give out my health information in the way it is described in this consent form until the end of the research study.

I have read this consent form, and I agree to take part in this study as explained in this consent form.

_____   _____
Date   Signature of Research Subject (subject is ≥18 years)

                                                              _____
                                                              Printed Name of Research Subject

I certify that I have explained the above to this research subject and believe that the signature was affixed freely. I also agree to answer any questions that may arise.

_____   _____
Date   Signature of Person Obtaining Consent

                                                              _____
                                                              Printed Name of Person Obtaining Consent

_____   _____
Date   Signature of Principal Investigator (if not listed above)

Printed Name of Interpreter: _____

Printed Name of Witness: _____

Signature of Witness: _____

APPENDIX I
SCD Demographics Survey
(Teen Demographics)

STUDY ID #_____

1. How old are you? _____

2. How old is your mother? _____ father? _____

3. Are you (   ) Female   (   ) Male

4. How do you describe yourself in terms of ethnicity? _____

5. What grade are you in? _____

6. Do you work? How many hours per week?
_____

7. Do you consider yourself to belong to a certain type or kind of religion such as Baptist, Lutheran or Catholic?

No   Yes, If yes what is it _____

If you go to church what type is it?
Denomination _____

8. How often do you go church each week? Church Attendance:
(   ) Attends 1-2 Times a Week
(   ) Attends 3 Times a Month
(   ) Attends Twice a Month
(   ) Attends Once a Month
(   ) Attends 6 Times a Year
(   ) Attends on Special Holidays/Occasions

9. Sickle Cell Disease Type:
_____

10. How many times have you stayed overnight in the hospital in the past year?
_____

11. About how many times have you stayed overnight in the hospital in your whole life?
A few 0-10
Some 11- 25
A lot 26 – 50

Too many to count, > 50
Number of Hospitalizations in lifetime:

_____

12. How many pain crises have you had this past year? Or during the last school

13. Have you ever had an operation? What type?

_____

_____

14. Have you ever had a transfusion? How many times?

_____

Appendix J
SCD Demographics Survey
(Parent Demographics)

STUDY ID#_____

1. Age_____   2. How would you describe yourself in terms of ethnicity
Ethnicity_____

3. Are you: Female_____ Male_____

4. Number of Children_____ Ages
_____

5. Do you consider yourself to belong to a certain type or kind of religion such as Baptist, Lutheran or Catholic?

No_____Yes, If yes what is it _____

If you go to church what type is it?
Denomination _____

6. How often do you go to church each week?

(   ) Attends 1-2 Times a Week
(   ) Attends 3 Times a Month
(   ) Attends Twice a Month
(   ) Attends Once a Month
(   ) Attends 6 Times a Year
(   ) Attends on Special Holidays/Occasions

7. Do you work? _____ How many hours per week? _____

8. Describe other persons in your
household_____
_____

9. Are you caring for other ill persons in the home?   NO   YES
If yes describe_____

APPENDIX K
SCD Interview Guide

(For Participant Who <u>Indicates Having</u> Religious Beliefs)

Today we are going to talk for one hour and tape the conversation. I'm interested in knowing more about you so I'll ask you questions about your life and your beliefs. First we are going to talk about you in general and about your faith and religious beliefs. There are no right answers. Please take your time answering each question. Answer each question in your own words. You do not have to answer each question or tell me things you are not comfortable sharing.

General:

1. Tell me about yourself.

   What kinds of things are you interested in?

   What types of things do you like to do?

   How would you describe your health?

2. Tell me about what or who is important to you in your life?

3. Tell me about some of your biggest difficulties or problems? How did you

   overcome them? How has this influenced your life?

4. Tell me about some of your proudest moments or biggest source of happiness.

   How has this influenced your life?

Now I am going to ask you a few questions about your thoughts on the meaning of life

5. Do you feel like there is meaning to people's lives? Are we here for a reason or

   purpose?

6. What do you feel is the purpose of your life? What gives your life meaning?

Religious Beliefs:

Now, I'd like to ask you a few questions about your religious beliefs:

7. If someone asked you about what the word religion means, how would you define

   religion?

8. Can you tell me a little about your feelings, thoughts, or beliefs regarding religion?

9. Tell me about your family's religious beliefs.

10. Tell me what kinds of things you consider religious?

11. Do you feel as though you have a relationship with a higher power? What do you call that higher power? Tell me about your relationship with a higher being (or God).

12. Tell me what your friends think about religion, God, church, faith?

13. What importance if any, do your beliefs have in your life?

Now I'd like to talk about how your religious beliefs influence your day–to-day life.

14. Do you think that people's religious beliefs have any type of effect on their health? If yes, what type of effect? How about for you personally, how do your beliefs affect your health? How?

15. Tell me about what sorts of things or people help you feel better when you are not feeling well or in the hospital?

16. How do religious beliefs influence the way people make decisions? Give me an example of how your beliefs have influenced your decisions or personal choices.

17. What role do your beliefs have during personal crisis? Give me an example of how you used your religious beliefs to deal with a personal crisis. How do you think you would have handled the crisis without your religious beliefs?

18. How and in what way would you expect religion to be included in your health care? Do you expect your nurses or doctors to ask about your faith or religion

when you are in the hospital? Has anyone ever talked to you about faith or

religion when talking about how to take care of your sickle cell? Tell me how

religion has been included in your care?

19. Are there any reasons why you would not want providers to include your religion

in your care?

20. Tell about the importance if any your beliefs have on illness?

Now, I'd like to know just a little bit more about how religion has or has not been a part of becoming who you are today:

21. Can you tell me a story about how your religion has influenced who you are

today?

22. Tell how your beliefs have changed from about 2-3 years ago (provide actual age

depending on participant age). How about 4-5 years ago (provide actual age

depending on participant age).

23. Is there anything else such as stories or experiences you would like to share?

24. Do you have any questions I can answer? Thank you for your time today.

APPENDIX L
SCD Interview Guide
(For Participant who Indicates **Not Having** Religious Beliefs)

Today we are going to talk for one hour and tape the conversation. I'm interested in knowing more about you so I'll ask you questions about your life and your beliefs. First we are going to talk about you in general and about your beliefs. There are no right answers. Please take your time answering each question. Answer each question in your own words. You do not have to answer each question or tell me things you are not comfortable sharing.

General:
1. Tell me about yourself.

   What kinds of things are you interested in?

   What types of things do you like to do?

   How would you describe your health?

2. Tell me about what or who is important to you in your life?

3. Tell me about some of your biggest difficulties or problems? How did you

   overcome them? How has this influenced your life?

4. Tell me about some of your proudest moments or biggest source of happiness.

   How has this influenced your life?

Now I am going to ask you a few questions about your thoughts on the meaning of life

5. Do you feel like there is meaning to people's lives? Are we here for a reason or

   purpose?

6. What do you feel is the purpose of your life? What gives your life meaning?

Beliefs (and Religion):

Now, I'd like to ask you a few questions about your beliefs:

7. If someone asked you about what the word religion means, how would you define religion?

8. Can you tell me a little about your feelings, thoughts, or beliefs regarding religion?

9. Tell me about your family's beliefs.

10. Tell me what kinds of things you consider important?

11. Do you feel as though you have a relationship with a higher power? What do you call that higher power? Tell me about your relationship with a higher being.

12. Tell me what your friends think about religion, God, church, faith?

13. What importance if any, do your beliefs have in your life?

Now I'd like to talk about how your beliefs influence your day–to-day life.

14. Do you think that people's beliefs have any type of effect on their health? If yes, what type of effect? How about for you personally, how do your beliefs affect your health? How?

15. Tell me about what sorts of things or people help you feel better when you are not feeling well or in the hospital?

16. How do beliefs influence the way people make decisions? Give me an example of how your beliefs have influenced your decisions or personal choices.

17. What role do your beliefs have during personal crisis? Give me an example of how you used your beliefs to deal with a personal crisis. How do you think you would have handled the crisis without your beliefs?

18. How and in what way would you expect your beliefs to be included in your health

    care? Do you expect your nurses or doctors to ask about your beliefs when you

    are in the hospital? Has anyone ever talked to you about your beliefs when

    talking about how to take care of your sickle cell? Tell me how beliefs have been

    included in your care?

19. Are there any reasons why you would not want providers to include your beliefs

    in your care?

20. Tell about the importance if any your beliefs have on illness?

Now, I'd like to know just a little bit more about how your beliefs have or have not
been a part of becoming who you are today:

21. Can you tell me a story about how your beliefs have influenced who you are

    today?

22. Tell how your beliefs have changed from about 2-3 years ago (provide actual age

    depending on participant age). How about 4-5 years ago (provide actual age

    depending on participant age).

23. Is there anything else such as stories or experiences you would like to share?

24. Do you have any questions I can answer? Thank you for your time today.

APPENDIX M
Final Coding Template

Name	Description	Hierarchical Name
A Way of Living	Expression of one's identity through action and relationships with self, others, the universe, and the sacred (Benson & Roehlkepartain, 2008) Beliefs, values, & commitments expressed & lived out daily & life is grounded in a sense of hope & belief Experiences of hope, meaning, or resilience in midst of hardship, conflict, & suffering. Person contemplates spiritual challenges & questions & identifies ways to live a life of strength	A Way of Living
Awareness	Act of being aware of one's self, others, and the universe in ways that nurture and develop meaning and a sense of identity (Benson & Roehlkepartain, 2008) Consists of finding accepting, seeking, creating, or experiencing a reason for being or a sense of meaning and purpose (Benson & Roehlkepartain, 2008)	Awareness
Beliefs (General)	Individual beliefs whether or not the participant verbalized having religious beliefs	Beliefs (General)
Beliefs and Decision Making	How one's beliefs does or does not influence how decisions are made	Beliefs (General)
Beliefs and Illness or Health	Participants thoughts on beliefs and impact during illness	Beliefs (General)
Beliefs on Purpose	Individual's beliefs on whether people are here for a reason	Beliefs (General)
Coping	Ways participants cope with problems	Coping
Expectations for Health Care Providers	Perception on health care providers and spiritual assessment	Expectations for Health Care Providers
Faith	Statements regarding faith	Faith

Name	Description	Hierarchical Name
Friend	One the participants identifies as a friend	Friend
Health Perception	The individual's perception of their health and may include physical or mental health as described by the individual	Health Perception
History of Spiritual Care	When participants indicate receiving spiritual care while ill, in the hospital, or in need	History of Spiritual Care
Identity Perception	Characteristics the individual identifies as belonging to himself or herself based on their perception	Identity Perception
Interconnecting	Finding, accepting, or creating profound significance & meaning in everyday experiences and relationships (Benson & Roehlkepartain, 2008). The person may experience a sense of love or responsibility for others & the world and becomes connected to certain beliefs, traditions, mentors, communities, & narratives; these remain significant over time & may create sense of belonging	Interconnecting
Interconnecting-God or a Higher Power, Transpersonal	Seeking, accepting, or experiencing significance in one's sense of the transcendent to include God or a higher power	Interconnecting
Interconnecting-Others or Creative Arts, Intrapersonal	Seeking, accepting, or experiencing significance in one's relationships with others	Interconnecting
Life Satisfaction	Periods in life that the individual has proud memories of	Life Satisfaction
Metanarratives	Stories, scriptures, historical moments shared	Metanarratives
Perceived Challenges	The individual's perception of experiences in life that may test their ability and call for support and/or resources within and possibly outside of the individual in order to cope	Perceived Challenges

Name	**Description**	**Hierarchical Name**
Religiosity	Expression of an individual's commitment to an organized way of knowing and orientating oneself to the religious community's subject of worship	Religiosity
Relationship is Personal-Private-Communal	Relationship with God or a Higher Power is personal, between the person and God, and the relationship is private, should only be discussed for the purpose of providing care, and the relationship is communal, as the person is a part of an organized religious community	Religiosity
Religion and Meaning	Individual's thoughts on the meaning of religion	Religiosity
Sickle Cell Experiences	A description of the individual's pain crisis experiences or other experiences related to their sickle cell disease	Sickle Cell Experiences
Support	Sources of social support	Support
Transcendence	To go beyond oneself and perhaps beyond human experience and understanding	Transcendence