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# Spirituality and Religiosity in Adolescents Living with Sickle Cell Disease

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**Abstract:** This study purports to address paucity in the literature regarding how adolescents with sickle cell disease (SCD) describe and experience spirituality and religiosity (S/R). This was a qualitative descriptive study. Two semi-structured interviews were conducted with nine adolescents ( $M_{age} = 16.2$  years). Data were analyzed using a template analysis style and a concurrent analysis process of data reduction. Three major themes encompassed the participants' descriptions of the relationships between S/R, health and illness in their lives including S/R as sources for coping, influence of S/R beliefs on health and illness, and sharing S/R with Health Care Providers (HCPs). S/R as coping mechanisms included six threads: interconnecting with God, interconnecting with others, interconnecting with creative arts, scriptural metanarratives, transcendent experiences, and acceptance and finding meaning. Expectations of health providers included two threads: Religiosity is private/personal and sharing spiritual and religious beliefs is risky. S/R are particularly salient for adolescents with SCD.

Keywords: spirituality, pediatrics, adolescent, sickle cell disease, religiosity

Sickle cell disease (SCD) is an inherited, multi-system chronic blood disease that shortens life expectancy and affects millions worldwide. SCD generates high health care usage and substantial morbidity and mortality. Bone marrow transplants have resulted in a cure for a small number of persons with SCD; however, this treatment is still not feasible for most patients (Fitzhugh, Abraham, Tisdale, & Hsieh, 2014). To manage their disease and mitigate complications such as pain, chronic anemia, disability, organ damage, infections, and early death, persons with SCD require ongoing comprehensive care.

Adolescents living with SCD face unique psychosocial challenges that interrupt daily routines, affect relationships, and effect overall well-being (Newland, 2008; Saris, Michaud, & Viner, 2004). Persons with SCD have fewer red blood cells, resulting in less oxygen delivery to cells throughout the body. Less oxygen, along with increased metabolic demands, may lead to delayed growth and sexual development, which can be very concerning to adolescents with SCD (Bennett, 2011; Sarjeant & Sarjeant, 2001). In addition, teens with SCD may have concerns regarding academic failure (Day & Chismark, 2006). SCD exacerbations and hospitalizations can negatively affect school attendance and attainment of educational goals. Persons affected by SCD have increased rates of cognitive delays, which may also affect academic achievement. Cognitive delays may result from abnormal patterns of brain maturation and strokes (DeBaun & Telfair,

2012; Puffer, Schatz, & Roberts, 2010; Sanchez, Schatz, & Roberts, 2010).

As teens approach adulthood, some become anxious about transitioning to adult services. Some adolescents believe that there are few adult providers specialized in the management of SCD. They fear that transition to adult care will be detrimental to their health and might hasten their deaths (Newland, 2008).

For the purpose of this study, *adolescence* was defined as the phase of human development that begins at the age of 10 years and extends to 19 years of age (World Health Organization, 2015). Adolescents' ability to cope may counter effects on their well-being and improve quality of life (Howard, Thomas, Rawle, Cartwright, & Westerdale, 2008). Spirituality and religiosity (S/R) are aspects of humanity that individuals often draw from to cope with life (Mahoney, Pendleton, & Ihrke, 2006; Pargament, Koenig, Tarakeshwar, & Hahn, 2004). *Spirituality* is the innate capacity of persons to transcend themselves, to discern and experience meaning and purpose in life through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003; Miller & Thoresen, 2003). *Sacred* refers to a divine being or ultimate truth as perceived by the person (Larson, Swyers, & McCullough, 1998). *Religiosity* refers to a commitment to an organized way of knowing and an orientation to a religious community's subject of worship (J. Schaefer, personal communication, July 15, 2010).

In previous studies, adolescents with SCD or their caregivers routinely engaged in S/R practices such as prayer, spiritual healing, and seeking God's love, forgiveness, and care as means to cope with their chronic condition (Anie, Stepsoe, Ball, Dick, & Smalling, 2002; Cotton, Grosseohme, & McGrady, 2012; Cotton et al., 2009; Sibinga, Shindell, Casella, Duggan, & Wilson, 2006; Yoon & Black, 2006). Adolescents with other serious chronic conditions including cancer, cystic fibrosis, and end-stage renal disease have also reported that their S/R help them cope (Haase & Phillips, 2004; Pendleton, Cavalli, Kenneth, Pargament, & Nasr, 2002; Snethen, Broome, Kelber, & Warady, 2004). The manner in which one copes with a chronic illness may potentially affect their health outcomes.

The connection between S/R and health, and the emerging research of psychoneuroimmunology (PNI) are particularly significant. PNI is a dynamic mechanism through which S/R-based coping may contribute to adaptive psychological and physiological responses to perceived stressors and thereby improve health and well-being. S/R-based coping exerts physiological effects by altering responses to stressors and influences the course of chronic conditions (Koenig & Cohen, 2002; Nassau, Tien, & Fritz, 2008). Effective S/R-based coping has been shown to improve the health of adults with chronic conditions (Berntson, Norman, Hawkey, & Cacioppo, 2008; Enstrom & Breslow, 2008; Koenig, George, Titus, & Meador, 2004). S/R-based coping may improve the health of adolescents with SCD. However, little is known about S/R, coping, and health among adolescents with SCD. Therefore, the purpose of this study was to explore how adolescents with SCD described and experienced S/R in their lives.

This study was guided by the Spiritual Development Framework (SDF; Benson & Roehlkepartain, 2008). The SDF is comprised of three processes. 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 identity. 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. A Way of Living is the expression of one's identity through action and relationships with self, others, the universe, and the sacred. Each process is embedded in, and interacts with, a variety of contexts and experiences over time. Spiritual development leads to physical, cognitive, affective, or social outcomes that may be positive or negative.

## **Method**

### *Research Design*

A qualitative descriptive design was used (Sandelowski, 2000). The aim of a qualitative descriptive study is to provide an in-depth description of the perspectives of the participants themselves with a low level of interpretation by the researcher (Sandelowski, 2000). The rich results can be used to develop interventions to improve health and well-being for this population.

## *Recruitment and Protection of Human Participants*

A purposive convenience sampling approach was used to recruit participants from a comprehensive SCD center located in a children's hospital in a large Midwestern city in the United States. The study was presented to eligible participants by a research associate or clinic physician. The eligibility criteria included (a) participants with a diagnosis of SCD, (b) participants who were English-speaking, (c) participants who were between the ages of 15 and 19 years. Participants were not questioned about their spirituality or religiosity during recruitment. If interested, names and contact information were forwarded to the Principal Investigator (PI). The PI met the participants and their parents at the next clinic appointment to explain the study. Parental consent and participant assent were obtained for adolescents less than 18 years. Participants who were 18 years or older provided consent. Eleven participants were recruited and nine participated. One participant withdrew prior to data collection and a second was not able to schedule interviews. This study was approved by appropriate institutional research review boards.

### *Participants*

The nine participants ranged in age from 15 to 18 years ( $M = 16.2$ ). Eight reported their ethnicity as African American and one as African American and Sicilian. All participants attended high school. Three were male and six were female. Religious denominations included Baptist, Catholic, Pentecostal, and Presbyterian. Six were regular church attenders (3 or more times per month). The hemoglobinopathy type for six participants was sickle cell anemia (HbSS), two had hemoglobin S-beta-zero-thalassemia (Hb $\beta^0$ /S), and one hemoglobin C (HbSC).

### *Data Collection*

Data were collected via a demographic survey (see Table 1) and interviews (see Table 2). An interview guide, developed by the PI, consisted of 24 open-ended questions accompanied by additional probes. Questions were designed to explore participants' views on their lives, health, and spirituality. Religiosity was explored if they held

religious beliefs. Participants completed two semi-structured audio-recorded interviews. Interviews were conducted by the PI in a private room with each lasting approximately 60 min. Participants received a US\$25 gift card after each interview. Recordings were transcribed by a professional transcriptionist.

## *Data Analysis*

Analysis of interviews consisted of three phases including data reduction, data display, and conclusion drawing and verification (Miles & Huberman, 1994). The PI listened to the recordings and verified transcripts to make corrections, remove identifiers, and gain a gestalt impression of the interviews. Transcripts and field notes were entered into NVivo 10. To begin coding, a template was created that included the three core developmental processes of the SDF (Miller & Crabtree, 1999). Additional codes were added as they were identified from the data. After coding the first interview of the first participant, the template included 14 codes. The template was used to code the second interview of the first participant. Another researcher independently coded the same two transcripts with the template. Comparison of the coding by the two researchers was approximately 80% in agreement. The PI reviewed both sets of coded transcripts to resolve discordance and refine the codes. Discordance was resolved in the process of code refinement, as some codes were collapsed into each other, some deleted, and some renamed. This process resulted in a template that included 18 codes. This final template was used to recode the transcripts from the first participant and applied to the remaining transcripts. Once coding was complete, data within each code were summarized in writing. The summaries were used to perform thematic analysis in which the PI looked within and across codes for relationships, patterns, and ultimately themes. Three major themes encompassed the participants' descriptions of the relationships between S/R, health, and illness in their lives including S/R as sources for coping, influence of S/R beliefs on health and illness, and sharing S/R with HCPs.

## *Trustworthiness*

To establish trustworthiness, the role of the PI as an instrument of data collection was considered (Denzin & Lincoln, 1998). The PI reflected on personal and professional experiences and views about S/R prior to interviewing participants to explore assumptions and limit bias. Prolonged engagement and respondent validation were used to ensure that the findings represented a credible analysis of the data from the participants' point of view (Lincoln & Guba, 1985). Transferability was achieved with thorough, rich descriptions of the findings and representative quotations to allow readers to determine the relevance of the findings to different populations (Lincoln & Guba, 1985). An audit trail consisting of observation, methodological, and theoretical notes was maintained to ensure confirmability (Lincoln & Guba, 1985). The PI documented observations about participants, the setting, and interviews. Methodological notes documented recruitment, data collection, and data analysis. Theoretical notes consisted of the PI's thoughts and hypotheses, reflections on interactions with participants, and on discussions with other researchers. Dependability was enhanced by comparing coding of two researchers and careful documentation of the method used in this study.

## **Results**

### *S/R as Sources for Coping*

As described earlier, S/R are related but unique human capacities. Spirituality is an innate aspect of humans, and religiosity is a chosen expression of spirituality. In this study, all the participants expressed that they drew from their spirituality to cope with the challenges that are part of having SCD. Most ( $N = 8$ ) of the participants claimed religious beliefs and described how they drew from their religiosity to cope with SCD. Males and females were similar in the value placed on their S/R. Spirituality-based coping encompassed interconnecting with others and with creative arts. Religiosity-based coping included interconnecting with God, scriptural metanarratives, and finding acceptance and meaning.



## *Spirituality as a Source for Coping*

Participants reflected on how they drew from their spirituality to cope. Their spirituality enhanced coping through their connections with others and their involvement in the creative arts.

### *Interconnecting with others*

Adolescents identified family members, friends, spiritual leaders, and other adults as providing spiritual support. Family was mentioned often in providing a spiritual foundation, prayer, and support especially when facing a pain crisis/illness. They also relied on family for communicating, advice, gatherings, and preparing their favorite foods.

Adolescents looked forward to interacting with friends while hospitalized and felt this helped them cope. Most indicated having at least one friend. Friends were of diverse ethnic and religious backgrounds, and adolescents verbalized developing a mutual respect for one another. Friends were described as being supportive by having fun, engaging in activities, talking, gaining insight, and visiting each other's church. Adolescents described experiencing connectedness through volunteering and service. Advocating for others assisted them in coping with their SCD.

Participants mentioned that their pastor/spiritual leader visited them when hospitalized and that their attentiveness and support was memorable and appreciated. HCPs and teachers were also mentioned as providing spiritual support. Having a caring attitude and a sense of humor were mentioned as qualities appreciated in pastors/spiritual leaders and other adults.

### *Interconnecting with creative arts/activities*

Adolescents described their connections with the creative arts and other activities as providing meaning in their lives. Through art, singing, music, dancing, acting, reading, and writing, adolescents described experiencing a level of connectedness that allowed them to express themselves, transcend their health issues, and feel relief from stressors faced. A 16-year-old female said, "I will just think about

dancing and it helps me feel better.” Specific activities used to experience transcendence included dancing, music, or reading. For one participant, writing in a diary was a way to reflect on Self, Others, and find meaning in experiences. Participants also reported a sense of connectedness with nature.

### *Religiosity as a Source for Coping*

Eight participants professed having religious beliefs and reflected on how they drew from their religiosity to cope with life and their health.

#### *Interconnecting with God*

Participants professed faith and felt that their relationship with God provided comfort when facing life challenges and in dealing with their SCD. They described their religiosity as consisting of a personal relationship with God that provided a foundation for their lives, and encouraged them to be better persons and to make the world a better place. In addition, their relationship with God helped them to have a different outlook on their experiences, and this was especially significant during stressful times. A 16-year-old female expressed how her relationship with God gave her direction. She said,

Having faith in God solidifies the whole. He’s like the father you can’t see, a father figure that puts everything into place. He causes everything to make sense and comforts you.

Adolescents in this study connected with God by praying, participating in religious services and traditions, reading the bible, reflecting on religious symbols, and repenting for their sins. They reported praying when life was going well and when encountering challenges with their SCD, staying current at school, and participating in extracurricular activities. Prayer occurred most often during pain crises and illnesses. A 15-year-old female commented on her relationship with God and how this influenced 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. So I

feel pretty strong in praying and just letting out all of my problems, or whatever is bothering me or my feelings to Him.

Another adolescent described his relationship with God. He said, "I have a deep belief in God, something to believe in, especially when things tend to look grim, He gives me hope." Having a relationship with God provided participants with a consistent source of comfort and strength.

Adolescents 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 challenges, but remained committed to their beliefs. Their S/R provided them with a positive outlook and inspired them to persevere. They believed that God was present with them during their most difficult moments and this was comforting. Some expressed that they did not have control over everything in life and that there are times when they had to surrender themselves and their situation to God. Participants said that they gave thanks to God when recovering from pain crises or illnesses because they felt they could not have handled it alone.

### *Scriptural metanarratives*

Participants believed that the Bible was a reminder of how to respond in everyday life. A 16-year-old female described how her religious beliefs and scriptural text helped when confronted with challenging situations. She said,

Because I have my religion and God's Word I'm more of like a calm person . . . like if I had an argument with somebody, you know, how it takes two to argue? When they're done arguing or whatever they have to say, I just sit and I'm like, Lord, please give me a Word and help us straighten it out, it just helps, it helps a lot.

A 17-year-old male shared, "There is always a scripture for you for the situation you're in." Reflecting on scripture was part of their routine, more often when in pain or facing challenges. Specific moments were mentioned when passages stood out from theology classes, conversations, or experiences and applied to a current situation. A 16-year-old male shared his belief in scriptural text, and

he said, "Scriptures get into your psyche, get into your spirit, and come back to you when needed."

Participants believed that reading the Bible provided wisdom and direction. Scriptural phrases referenced by participants included, ". . . by His stripes we are healed" and "Fear not, for I am with you." There were also phrases 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." Participants expressed their gratitude and application of scriptural text.

### *Acceptance and finding meaning*

Adolescents indicated that their religiosity shaped their morals and provided a frame of reference for reflection and decision making. Many indicated that their beliefs kept them looking toward the future and thinking about contributions they would make as adults. Embracing the diversity of 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.

Adolescents verbalized acceptance of their SCD and held the belief that their experiences were part of their purpose in life. Participants expressed that trials propelled them "to another level in life" and assisted in developing perseverance. One 15-year-old male compared his sickle cell pain crises to Jesus's experiences of being beaten and stoned. He said, "If Jesus experienced pain, I can bear this and come out a stronger person." Participants believed that it was important to use their experiences to help others by advocating for improved care for those with SCD. A 16-year-old female described her experience in helping others. She said, "I started a [an advisory] board for kids with sickle cell . . . we are just kind of giving our input."

### *Influence of S/R Beliefs on Health and Illness*

Many expressed that a healthy lifestyle follows living according to Godly principles and that this could affect their health. One 16-year-old adolescent shared her thoughts about her beliefs and health. She said, "He gives me the mindset to focus on how I can better my

health, instead of waiting for him to perform a miracle, kind of help Him to perform a miracle.”

Some expressed that one's life span could be shortened based on their behavior toward 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. As one participant shared,

When I'm sick, or when I'm going through a crisis, it's good to know that there's a God who's bigger than me, bigger than sickle cell, bigger than sickness and disease in general . . . He's going before you to make your way easy and successful.

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 enjoyed when their physical condition would not allow them to participate in the activity.

Faith was described as being meaningful to rely on during illness or difficulties and provided hope, strength, and support. A common belief was that a relationship with God was needed to focus and improve health. It was significant not take their health or life for granted.

### *Sharing S/R With Health Care Providers*

All the participants discussed sharing S/R beliefs with HCPs. They held different views regarding whether providers should assess S/R among their adolescent patients. Many believed that if beliefs intersected health or illness, then the information should be included in an assessment. Some indicated that providers should observe their patients to understand their beliefs/faith. A 16-year-old female said, “If it appears as if I need quiet time to pray, this should be honored without asking.” Some felt completing an assessment of beliefs was not expected, but would be welcomed if part of a general assessment. They recommended that providers discuss S/R respectfully. Participants felt that questions that were perceived as judgmental

would make adolescents uncomfortable and would inhibit their responses. Participants indicated that their S/R was generally not assessed or included in their care. Four participants reported that spiritual care was provided to them on limited occasions by their HCPs. One participant described the spiritual care provided by an HCP as "refreshing." Participants mentioned a primary care provider, a hematologist, a nurse, and social workers as providers who provided S/R support and encouraged them to rely on their faith.

Participants described their S/R as personal and private. Personal described the relationship between God and themselves. They viewed their S/R as part of their experience, and it was private for them. A view of S/R as private also meant their relationship with God should not be discussed with others. Adolescents indicated that sharing their beliefs with HCPs could be risky and feared being misinterpreted. They also expressed concern that conflicting faiths or religious beliefs held by adolescents and providers might result in negative outcomes. Adolescents were concerned that sharing their S/R beliefs with providers might lead the providers to dismiss their physical needs or to treat them differently because of their S/R beliefs. When a 15-year-old male was asked to share his opinion on HCPs assessing his beliefs he said, "I prefer they not ask me, I don't want them to treat me any different than they do right now." They were also concerned that providers would gossip about their S/R beliefs. Participants disclosed their desires to be treated fairly once their S/R beliefs were known. A 16-year-old female said, "I don't want to scare someone off with the topic of religion." Adolescents desired to be treated as a whole person and not be defined by their S/R beliefs.

Participants believed that adolescents may not want S/R beliefs to be included in their health assessment, and therefore may be reluctant to share this information with their HCPs. Sharing information was generally felt to be okay if the purpose was to accommodate beliefs. Some adolescents expressed the desire for a similar belief system between the provider and teen to accommodate inclusion of S/R in their health care. As one 16-year-old female shared, "If the person has different beliefs, I wouldn't want to put them in that position, cause . . . it could be uncomfortable." The ability to trust the individual performing the assessment was significant. Providers engendered trust when they conveyed that they knew the adolescents

personally, anticipated and responded to their needs, paid attention to them, and provided humor and respect.

## **Discussion**

Findings from this study provided evidence that participants drew from their spirituality and most drew from religiosity to enhance coping with SCD. Adolescents were descriptive in communicating how their beliefs and experiences shaped their identity. The SDF used to guide this study was appropriate and provided a lens for understanding the processes of spiritual development (Benson & Roehlkepartain, 2008). Adolescents verbalized how they used their SCD experiences to help others, inform communities, and advocate for adolescents with SCD.

In the current study, adolescents participated in a collaborative relationship with God and believed "I have to do my part." Adolescents believed caring for their bodies was significant if they expected God to help them feel better. Taking prescribed medications, eating healthy, and treating others with respect were important for healthy outcomes.

Adolescents considered their relationship with God to be personal and felt their S/R beliefs should not be openly shared with others. While this was a common belief among the adolescents interviewed, most indicated that assessment of S/R beliefs would be acceptable for the purpose of enhancing overall health. A few adolescents provided instances where HCPs provided S/R care. They indicated being open to receiving S/R care from the HCPs. Prior research conducted with children with asthma revealed that having their S/R addressed was contingent on the acuity of the clinical event (Cotton, Grosseohme, Bignall, & Weekes-Canu, 2013). The complexity of SCD may cause adolescents to rely more on their S/R to cope. Adolescents in the current study welcomed S/R assessment but indicated that the interaction presented by the HCP on assessment can influence their level of responses. In another study, adolescents indicated that having an HCP who gave consistent care, maintained confidentiality, and conveyed a caring attitude were behaviors they preferred (Schaeuble, Haglund, & Vukovich, 2010). Interactions between adolescents and their HCPs may affect health assessment completion and inclusion of pertinent S/R information.



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. Exploring the S/R of adolescents' parents is warranted as participants in the current study often mentioned parents as having influence on their S/R. 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 HCPs. S/R needs of adolescents and their families can be assessed to provide optimal holistic care. Males have been noted to experience more negative religious coping than females (Bediako et al., 2011). Males and females were comparable with regard to the significance of S/R in their lives in this study. Exploring gender differences in adolescents' S/R experiences into adulthood may lend additional insight. Examining global differences in S/R coping mechanisms would allow for comparisons to be made across populations. HCPs could also be included in future research to allow for comparisons to be made between providers' and adolescents' attitudes and opinions regarding the relevance of S/R in health and health care. An enhanced understanding of how providers and adolescents approach S/R and health can facilitate improved provider-patient communication and relationships. Finally, in a previous systematic review of literature, a lack of consistent definitions for S/R was identified (Rew & Wong, 2006). Findings from the current study can be used to direct future research and gain a greater understanding of how adolescents use these terms.

Recognizing that all persons have spirituality, it is important that providers consider assessment of spirituality with all patients. Also recognizing that not all patients would like to discuss this topic, providers should first ask if it is ok to talk about spirituality. If teens are willing, inclusion of preferences and beliefs will contribute to a thorough assessment and allow providers to develop deeper understanding of their patients. Coping with a chronic illness during adolescence can be stressful. This may be alleviated by addressing S/R needs and seeking approaches to improve the patient-provider relationships. HCPs are in an optimal position to integrate S/R into plans of care when appropriate and allow for greater provision of holistic care.



Participants in this study comprised a specific group with limited heterogeneity. They all had SCD, most were African American, and they were close in age. Nearly all of them professed religiosity and belonged to Christian denominations. The participants also received specialized care at a well-supported sickle cell clinic. Thus, the findings may not fit other populations of adolescents. Another potential limitation was response bias, for adolescents may have answered questions in a manner they felt would please the PI. They may also have withheld information. Finally, teens may have chosen to participate because they wanted to share their experiences regarding their S/R. Their views on S/R may not be shared among all teens living with SCD.

Results from the current study highlight the significance of examining S/R in an age-specific population. S/R are salient for adolescents with SCD. The adolescent participants in the current study relied on their S/R beliefs, activities, and relationships to face challenges. Attending to the S/R experiences of adolescents and assisting them in expressing their beliefs in a supportive environment can nurture their development and assist them in coping with health matters and concerns. Supporting their S/R 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 to 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 affect the meaning adolescents ascribe to their experiences and nurture their spiritual development.

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**Table 1.** Participant Demographics.

Participants N = 9	
Frequency of church attendance	
1-2 times/week	5
3 times/month	1
Once per/month	2
Special occasions	0
>1 year	1
SCD type	
HbSS	6
HbSC	2
S $\beta^0$ thal	1
Times in hospital past year	
None	1
1	4
2	2
5	1
11	1
Times in hospital over life	
0-10	2
11-25	2
26-50	2
>50	3
Pain crises past year	
1-2	4
4	1
10-20	1
20+	1
30-36	1
Had operation	
Yes	5
Gall bladder	4
Lymph nodes	1
Spleen	1
Tonsils	2
No	4

Note. SCD = sickle cell disease.

**Table 2.** Interview Guide.

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SCD Interview Guide (Indicated Having Religious Beliefs)

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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. **(Tell me about your family's beliefs.)**
10. Tell me what kinds of things you consider religious? **(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 (or God). **(Tell me about your relationship with a higher being.)**

12. Tell me what your friends think about religion, God, church, and 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.

**(Now I'd like to talk about how your beliefs influence your day-to-day life).**

14. Do you think that people's religious beliefs have any type of effect on their health? **(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 religious beliefs influence the way people make decisions? **(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 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 **(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 religion has influenced who you are today? **(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.

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Note. Alternate format of interview question for those who denied having religious beliefs in bold. SCD = sickle cell disease.