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Religious Coping and the Use of Prayer in Children With Sickle Cell Disease

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Abstract

Background—While adolescents and adults with sickle cell disease (SCD) have reported using religion to cope with SCD, there is no data examining religious coping in young children with SCD. The purpose of this qualitative study was to: (1) describe the types of religious coping used by children with SCD; (2) describe the content and frequency of prayer used in relation to SCD; and (3) examine how children viewed God/Higher Power in relation to their SCD.

Procedure—Children with SCD participated in a semi-structured interview and an art drawing exercise focused on the use of general coping and religious coping. Interviews were coded, organized, and analyzed using a template organizational style of interpretation and NVivo 8.0 qualitative software.

Results—Of the 19 participants, the average age was 8.05 years ($SD \pm 1.81$); 11 were female (58%); all (100%) were African-American and 9 (47%) were Protestant. Children used religion to gain control, make meaning, and find comfort. Most children reported praying to get well, to keep from getting sick, and to get out of the hospital. Children described a functional God who made them take their medicine or took them to the hospital and an emotional God who made them happy and comforted them when they were sad or scared.

Conclusions—These children with SCD reported using religion to help cope with the illness. Providers should be aware of the importance of religion to many of these children and integrate religion, as appropriate, into discussions about coping with SCD.

Keywords

children; coping; religion; sickle cell disease; spirituality

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INTRODUCTION

Sickle cell disease (SCD) is an inherited hematological disorder characterized by atypical red blood cells that sickle, and cause severe and unpredictable pain episodes [1]. Affecting 1 in 500 African Americans, SCD can result in long-term complications such as stroke, kidney failure, risk for increased infections, and a shorter life span [2]. Children with SCD often have disruptions in daily activities such as school and miss nearly twice as many days of school as their healthy peers [3]. The illness has also been associated with adjustment difficulties, including increased depressive and anxiety symptoms [4]. Given the significant psychosocial implications of SCD, studies examining the ways that children cope with SCD are warranted in order to inform clinical interactions aimed at improving coping and ultimately health outcomes.

Many factors contribute to how a child copes with having a chronic illness such as SCD. These include disease factors, personal factors, family factors, and social factors that operate together to determine how well a child will cope [5]. One factor that is less well described but that may help children cope with a chronic illness such as SCD is religion or spirituality [6,7]. To date, however, there is little available information on the use of religious/spiritual coping by children or adolescents with SCD [8]. Religious/spiritual coping is defined as how individuals or families use religion and/or spirituality to deal with a stressor, such as a chronic illness [9]. One of the most often referenced typologies for use of religious coping is that of Dr. Kenneth Pargament's in which he describes religion as being used to: (1) gain control/problem-solve, (2) make meaning, and/or (3) derive comfort or intimacy with the Divine [9].

In a recent study we conducted with adolescents ages 13–19 with SCD, 35% of participants reported praying once a day or more for symptom management [8]. In addition, adolescents reported using both positive religious coping (e.g., sought God's love and care [73%]) and negative religious coping (e.g., decided the Devil made this happen [30%]) strategies, though positive strategies were endorsed significantly more so than negative strategies [8]. More than half of the parents of these adolescents reported using positive religious coping strategies such as seeking God's love and looking for a stronger connection with God to deal with their child's illness. Furthermore, in adults with SCD, greater endorsement of positive religious coping (e.g., seeking spiritual support from God/Higher Power) has been associated with significantly fewer hospital admissions [10], and attending church one or more times a week has been associated with lower scores on pain measures [11], even after controlling for related covariates.

Given these findings and the particular salience of faith in the African-American community [12], we were interested in whether young children with SCD would report using religion and prayer to manage the pain and other difficulties associated with the disease. If children with SCD do use religious coping, medical providers who care for these children need to be aware of this coping method in order to integrate it into discussions of pain and disease management. As quantitative measures of religious coping have not yet been validated in children under the age of 10, we chose to use qualitative methods, including semi-structured interviews and art drawings, to explore the use of religious coping in this population.

Therefore, the overall purpose of this pilot study was to examine the use of religious coping in children with SCD. Specifically, we wanted to: (1) describe the types of religious coping used by children with SCD; (2) describe the content and frequency of prayer used in relation to their disease; and (3) examine how children viewed God/Higher Power in relation to their SCD. We hypothesized that children with SCD would report using religion, particularly prayer, to cope with having SCD. We also hypothesized that children would view God/Higher Power primarily as a positive figure who helps them cope with having SCD.

METHODS

Participants and Procedures

Twenty children (ages 5–10 years) were consented/assented to participate in a semi-structured interview and an art drawing during the 2009 Sickle Cell Research and Education Day and Zoo Day annual events held at Cincinnati Children's Hospital Medical Center (CCHMC) in Cincinnati, OH. The events are designed to be family-friendly opportunities for children with SCD and their family members to learn about and participate in research and educational events related to SCD.

One child did not begin the interview due to lack of time. Given the unique nature of the research method (interviews done simultaneously with different interviewers and with competing educational opportunities at the events), not all remaining 19 participants completed all parts of the study. Fifteen of the remaining 19 children completed interviews, though one child's interview was not usable due to her young age and difficulty comprehending the questions. Four children completed drawings only due to a lack of time to complete the full interview. Therefore, for purposes of this study and analyses, we included a total of 14 interviews and 19 art drawings.

Eligibility criteria for this study were ages 5–10 years, the ability to comprehend English, and a diagnosis of SCD. Participants were recruited via letters mailed prior to the events and in person at the events. All participants and their parents who were approached at the events agreed to participate in the study. Parental/caregiver permission and child assent were obtained. During the consent process, parents/caregivers were asked for their child's preferred term for “God” or a “Higher Power” as well as permission to allow their child to draw an image of God/Higher Power. All parents/caregivers consented to this procedure. Parents/caregivers then completed a demographic questionnaire and children participated in a semi-structured interview and two art drawings. Parents/caregivers were compensated \$25 and children were provided with a coloring book and crayons for their participation. All study procedures were approved by the CCHMC Institutional Review Board.

Measures

Demographic and clinical variables—Demographic and clinical information was provided by the child's parent/caregiver. Demographic items included: child's birth date, gender, ethnicity, grade, religious preference, and the caregiver's highest education level and religious preference. Clinical information, including current SCD medications and SCD

related hospitalizations and emergency room visits within the last year, were obtained via chart review.

Semi-structured interview and drawings—Each child participated in a semi-structured interview with one of four investigators. Interviews were conducted individually in private areas or rooms and lasted approximately 20–30 minutes. All interviews were audio-taped, transcribed, and double-checked for accuracy. Content of the interviews were modeled after a protocol developed by Pendleton et al. [6] to examine religious/spiritual coping in children with cystic fibrosis and previous literature on children and religious coping [7,13]. As in the study by Pendleton et al. [6], art drawings were used in conjunction with verbal interview questions to elicit coping information in a developmentally relevant manner. The interviews were primarily comprised of questions related to general and religious/spiritual coping. For example, interviewers asked children to “Draw a picture of the things in your life that help you deal with being sick” (general coping). Children were then asked about the use of prayer and God's feelings about them having SCD and were asked to “Draw a picture of you and God” (or other preferred term for a Higher Power) “when you are sick/in pain” (religious/spiritual coping). Probes and follow-up questions were used as necessary to explore the child's responses. If a child responded “no” to whether God helped him/her when in pain or sick, the interviewer continued to the next section and did not ask the child to draw a picture of God/Higher Power.

Data Analysis

Interviews were coded, organized, and analyzed using an iterative template organizational style of analysis as described by Crabtree and Miller [14]. This style of interpretation involves: (1) creating a code manual or coding scheme, (2) hand or computer coding text, (3) sorting segments to group similar texts in one place, and (4) making connections within and between segments that are then corroborated and legitimized [14]. Consistent with these procedures, interview transcriptions were first imported into standard qualitative software package NVivo Version 8 [15] for data organization, coding, and analysis. Second, two authors independently reviewed transcripts to identify major themes (termed codes in NVivo). Initial themes were discussed and consensus was reached on what major themes would be coded in the transcripts. After this code manual was agreed upon, the two authors coded all transcripts together and resolved any differences of opinion on codes through discussion, negotiation, and eventual consensus [16,17]. This step resulted in sorting many segments of text into more manageable chunks or groupings. Any similar or overlapping nodes were then collapsed or condensed in order to limit overlap in the final representation of the data.

A second set of analyses were completed to code for adult-specific religious coping strategies previously identified by Pargament [9] and child-specific religious coping strategies previously identified by Pendleton et al. [6]. Following this coding process, individual nodes for the final coding scheme were compared using the Attributes feature in NVivo to examine the pattern of node responses by age and gender. The final step of corroboration and legitimizing the data occurred when the authors visually displayed the

data, discussed connections between and across the segments, and finalized the major story of the data.

In addition, the two sets of drawings were examined visually by the authors for content and themes. Drawings were grouped together (general coping and religious coping) for purposes of initial comparison and contrasting. Given the focus of this paper, further examination of the drawings was limited to the drawings of God and the child (religious coping). Drawings were examined for similarities and differences in areas such as: what function or role that God was playing in relation to the child's illness; the placement of God as next to or above the child; the size, shape and representation of God; and whether there was physical contact between the child and God (e.g., hugging).

RESULTS

Of the 19 participants, the average age was 8.05 years ($SD\pm 1.81$) (Table I). Eleven participants were female (58%), and all (100%) were African-American. The most commonly endorsed religious preference (47%) was Protestant. Forty-seven percent of participants had at least one ER visit for SCD that did not result in an inpatient hospitalization. In addition, within the past year, over half (53%) of the participants were hospitalized, many after first visiting the ER for SCD-related issues.

Summaries of findings in the three major areas that were examined (types of religious coping, use of prayer, and function of God) are presented below. Illustrative quotes representing each of the major areas/themes are presented in Tables II–IV. Accompanying related drawings are displayed in Figures 1 and 2.

Types of Religious Coping

Participants reported using religion in a variety of ways to cope with SCD. The majority of children described using religion to gain a sense of control when sick or in the hospital (Table II for illustrative quotes). Children also described religion as helping them make meaning out of a stressful or unpredictable life event, in this case, living with SCD. A few described using religion and God for comfort when in pain or distress. A couple of children reported being disappointed or dismayed with God's response to his/her illness, believing that if God knew they were there and in pain, that He [God] would have helped them more.

Use, Content, and Efficacy of Prayer

Over half of these children reported using prayer or religion to manage SCD. Children described praying for themselves or others praying for them in relation to their illness. Most self-prayers were about getting well, hoping they would not get sick, feeling better, or getting out of the hospital (Table III for illustrative quotes). When asked if praying worked to help them feel better, the most common answer was sometimes, followed by yes, with only a few saying prayer did not work at all to take the SCD pain away. When asked if they thought whether or not their parents or family members pray for them to get well, most children said yes. Of note, the majority of children who said their families pray for them, when asked, reported that family prayer was also efficacious in helping them feel better. One child even said that God was praying for her.

Function of God

In an effort to understand in what ways and why some children might turn to God to cope with their SCD, we asked children to draw a picture of him/herself and God/Higher Power when he/she is sick and to then tell us a story about the picture. In general, children described God in one of two ways—as either a functional God or an emotional God (Table IV for illustrative quotes). Five children described God as having both of these functions. A functional God did practical things for the children; for example, taking them to the hospital, making them take their medicine, stopping their pain, or healing them. While the children could not exactly describe what God did or how God intervened, most were sure that He did something to help them feel better. Of note, oftentimes God worked on the children to make them feel better while they were asleep (Fig. 1). God also functioned at times at a child's direct request, for example one 9-year-old male asked God directly to put him back in his body when he thought he was about to die in the hospital.

Children also described an emotional God in relation to their SCD. This God provided comfort for children when they were in pain, made them happy, and made their hearts smile. Some children described and drew pictures of the tactile act of God hugging them, holding hands, or performing other acts to help them feel better (Fig. 2). Children were also asked to describe what they think God feels about them having SCD. Given the choices of mad, glad, sad, or scared to choose from, most responded that God was sad for them, followed by do not know, and scared. One 7-year-old male said that God hopes that he does not die. No child described God as being glad or mad that he or she had SCD.

DISCUSSION

The purpose of this study was to explore the use of religious coping in children with SCD. Over half of these children reported using prayer or religion to manage SCD—a number similar to that reported by adolescents with SCD, adults with SCD, and caregivers of children with SCD [8,11,18]. Using Kenneth Pargament's religious coping styles as a primary frame of reference [9], we found that these children used their religious beliefs to gain a sense of control over their illness, construct meaning out of their illness experiences, and for comfort and closeness to the Divine.

Very few studies have examined the use of religious coping in children with a chronic illness. In a qualitative study of 5–12 year olds with cystic fibrosis (CF), which the current study was modeled after, Pendleton et al. [6] found that children with CF reported a variety of religious/spiritual coping strategies that were typically associated with adaptive health outcomes. In a study of 87 adolescents hospitalized for asthma, those who used positive religious coping strategies (e.g., sought spiritual support from God/Higher Power) had better adjustment and less depression than those who did not use these strategies [7]. While the children in this study reported a much smaller range of religious coping strategies than described in previous studies [6,8], this is likely due to a methodological difference rather than a true difference. For example, we did not ask children to respond to specific predetermined coping strategies as in prior studies [6,8], but rather allowed the children to spontaneously describe how they used their religion. Interestingly, negative religious coping styles were not spontaneously raised by the children in this study. In our previous

quantitative study of adolescents with SCD, participants endorsed some negative religious coping styles, including feeling that SCD is a punishment from God and/or that SCD is the work of the Devil. Further exploration of negative coping styles in children with SCD is warranted given that the use of such strategies in adults has been associated with negative health outcomes, including reduced health-related quality of life, increased depressive symptoms, and higher mortality rates [19].

As hypothesized, the children in our study reported using prayer to manage their disease and their experience with having SCD. In our previous quantitative study of 151 urban adolescents with asthma, 61% reported using prayer once a day or more for symptom management [20], and in our study of 48 adolescents with SCD, 35% reported praying once or more per day in relation to their illness [8]. In this study, the children's prayers were most often about getting well, hoping they would not get sick, feeling better, and/or getting out of the hospital. The use of prayer to change one's situation (e.g., heal me, get me out of the hospital) is considered to be pleading in Pargament's typology of religious coping styles [21], and has been associated with positive outcomes such as more positive affect [22] and negative outcomes such as increased depressive symptoms and poorer psychological status [23,24]. Previous studies with adolescents have shown that while they may endorse using prayer to manage symptoms, few tell their provider they are doing so [20]. Future work should examine how to integrate these conversations comfortably with patients in a way that supports their individual styles of coping while remaining culturally sensitive to differing religious beliefs and varying styles of patient-provider communication.

As part of this pilot study of religious coping, we were also interested in how children would describe and depict God/Higher Power in relation to their SCD. Many children depicted God as a functional God, which is similar to Pendleton's work with children with CF in which 39% of 5–10 year olds described God as interventional. Our finding is also consistent with Mercer's activist metaphor in which children's spirituality is expressed in relation to action [25]. Experiencing God as solving a child's problems has also been previously described in children's dreams [26]. At the same time, the practical functioning of God described by these children as healing them, giving them medicine, and/or taking them to the hospital is consistent with Pargament's descriptions of adults coping through problem-solving to control an outcome [9]. Since many children viewed God in this practical, problem-solving capacity, enlisting this type of spiritual support through discussions of coping with children may be useful and relevant for them in the clinical encounter and/or at home.

The fact that some of these children spontaneously verbalized a relationship between their religious lives and adhering to recommended health care bears consideration. Some children stated that God took them to the hospital or helped them by telling them to take their medicine. While few would agree concretely that God actually gave them their medicine or transported them to the hospital, the importance of the underlying attribute and belief that God helped them with adherence to medical regimen is important. For example, utilizing religious language relevant to a particular child/family may help the child connect his/her religious beliefs with medical actions that ultimately may prove beneficial to the patient.

Children also described God in a supportive or emotional role in which God helped them, comforted them, and was there for and with them in times of need. This role parallels Pendleton's description of Belief in God's Support in children with cystic fibrosis, a religious coping strategy in which God assists, benefits, protects, and comforts the child [6]. It is also consistent with Pargament's seeking spiritual support coping style [27] in which people seek to gain comfort and closeness to God, including trusting that God would be by their side and look to experience God's presence in the midst of a stressor. The resilience literature in child development supports the notion that children who have at least one supportive role model in their life tend to fare better in general and are more resilient in the face of adversity [28]. This supportive God that many children described may serve as such a role model and source of support and comfort in the face of an adverse situation such as living with SCD.

Our study has several limitations worth noting. The sample was comprised of a convenience sample of children followed by one SCD clinic in one geographic location and thus may not be representative of other children with SCD. However, often a goal of qualitative research is not generalization, but rather hypothesis generation or exploration of a topic in more depth [29] as was seen in our study. In addition, the use of this qualitative method did not allow for the examination of the relationship between the use of religious coping and specific quantifiable outcomes. As a result, it is not possible to draw conclusions regarding a statistical association between the use of positive versus negative religious coping styles and key health outcomes. Third, our study did not assess the role of religious coping in parents of these children with SCD, an important factor to consider in children with a chronic illness [30]. Nevertheless, important conclusions can still be drawn.

Our findings underscore the importance of considering religious/spiritual issues and how they relate to coping and, ultimately caring, for children with a chronic illness such as SCD. These children with SCD reported a prevalent use of religious coping, primarily prayer, to cope with the unpredictable and painful nature of the disease. They described God as both a supportive and a functional God who did very practical things for them like make them smile, help them feel better, and/or tell them to take their medicine. The stories they told of God in relation to their illness were clear and detailed, though the children were not sure how exactly God helped them, they knew that He helped them somehow. Clinicians working with children with SCD and their families should be aware of the relative importance of religious beliefs and religious coping in this population and consider integrating this into conversations of coping, adherence, and support whenever possible and appropriate. Future studies should examine how to best integrate issues of religious coping into clinical conversations that are practical for the clinician, useful for the family, and will ultimately enhance health outcomes for children with SCD and their families.

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Fig. 1. When describing his picture a 9-year-old male noted, “I’m asleep and He’s putting the zap on me: `Stop!” When probed by the interviewer, “Stop what?” the male replied, “the pain.”



Fig. 2. When asked to describe the picture she had drawn of her and God when she was sick, this 10-year-old female said. “That’s God-... that’s the sun.” The interviewer said “That’s the sun and it’s shining?” To which the female replied. “The shine, He’s putting it down...I think it’s supposed to make me feel better.” [Color figure can be seen in the online version of this article, available at <http://wileyonlinelibrary.com/journal/pbc>]

TABLE I

Demographic and Clinical Characteristics

Variable	
Age, M (SD) years	8.05 (1.81)
Gender, N (%) female	11 (58)
Race/ethnicity, N (%) African-American	19 (100)
Religious preference, N (%) ^a	
Protestant	9 (47)
Catholic	3 (16)
None	3 (16)
Other	3 (16)
Highest level of parental education, N (%) ^b	
Did not finish high school	2 (11)
High school diploma or GED	2 (11)
Completed some college	5 (26)
Graduated from college	7 (37)
Sickle cell medications, N (%) yes ^c	
Hydroxyurea	7 (37)
Transfusions	2 (11)
Ex-Jade	2 (11)
None	9 (47)
Number of hospitalizations in past year, N (%)	
0 hospitalizations	9 (47)
1 hospitalization	7 (37)
2 hospitalizations	2 (11)
3 hospitalizations	1 (5)
Number of ER visits in past year, N (%)	
0 ER visits	10 (53)
1 ER visit	5 (26)
2 ER visits	4 (21)

^a n = 18;

^b n = 16;

^c Medication use not mutually exclusive.

TABLE II

Types of Religious Coping^{*,**}

Illustrative quotes	Pargament's coping style	Pendleton's coping style
<p>Int: Can you tell me what kind of things you pray about or talk to God about?</p> <p>Ch: Like God please help me get out of this hospital and make me feel better (9-year-old male)</p>	Control (Pleading)	Petitionary religious/spiritual coping
<p>Int: What do you think God thinks about you having Sickle Cell?</p> <p>Ch: He thinks that he can help me if he can (7-year-old female)</p>	Meaning (Reappraisal of God's Power)	Benevolent religious/spiritual reappraisal
<p>Int: So would you say that God or prayer or anything helps you with your Sickle Cell Disease or with your pain?</p> <p>Ch: ...when I'm in pain, I just pray...but I don't get what I want sometimes...I just ask...I ask something and then it doesn't come out right so...I ask for a lot of things...About like giving my pain away or something wrong or whatever and all that stuff and then I will stop, go to sleep, and then it doesn't happen (9-year-old male)</p>	Comfort (Spiritual discontent)	Discontent with God

* Illustrative quotes have been slightly edited to increase readability;

** "Int" refers to the Interviewer and "Ch" refers to the child/participant.

TABLE III

Content and Efficacy of Prayer^{*,**}

Illustrative quotes	
Content	Int: Anything about your Sickle Cell Disease that you are praying about?
	Ch: Yes. I hope I don't get sick (7-year-old male)
	Int: Do you ever talk to God?
	Ch: Yes. How I don't want to be sick anymore (6-year-old male)
Efficacy	Ch: Jesus please help me feel better and heal me, and help me do some exercises so my stomach won't be hurting no more and that's all
	Int: Does it ever help you to pray?
	Ch: Um-hm. (shakes head affirmative) In a thankful way (8-year-old male)
	Int: What do you say when you pray when you're in pain?
	Ch: I say please help me
	Int: Does God respond to you?
	Ch: I don't know (10-year-old male)

* Illustrative quotes have been slightly edited to increase readability;

** "Int" refers to the Interviewer and "Ch" refers to the child/participant.

TABLE IV

Function of God^{*,**}

Illustrative quotes	
Functional Role	Ch: God take me to the hospital because God gives us our soup to make us feel better so... Mommy and daddy they go home and I stay at the doctor...and I see Jesus coming to take me to the hospital
	Int: Does He actually take you to the hospital?
	Ch: Yeah... He does. But He takes me to the hospital so I can feel better cuz I was sick (6-year-old female)
	Int: What does He (God) do to make you feel better?
	Ch: By telling me to take my medicine (10-year-old female)
	Int: What's He [God] doing about your Sickle Cell Disease when you're sick?
	Ch: He heals me. Touches me, heals me...(9-year-old male)
Emotional Role	Int: Do you feel like God can help you get better when you are sick?
	Ch: (Nod yes) He makes me happy
	Int: How does he make you happy?
	Ch: He just smiles (6-year-old female)
	Int: And what is God doing in the picture?
	Ch: Giving me a hug
	Int: And what happens when he gives you a hug?
	Ch: I feel better (6-year-old male)

* Illustrative quotes have been slightly edited to increase readability;

** "Int" refers to the Interviewer and "Ch" refers to the child/participant.