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Religious/Spiritual Coping in Adolescents with Sickle Cell Disease:

A Pilot Study

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Abstract

Religious/spiritual (R/S) coping has been associated with health outcomes in chronically ill adults; however, little is known about how adolescents use R/S to cope with a chronic illness such as sickle cell disease (SCD). Using a mixed method approach (quantitative surveys and qualitative interviews), we examined R/S coping, spirituality, and health-related quality of life in 48 adolescents with SCD and 42 parents of adolescents with SCD. Adolescents reported high rates of religious attendance and belief in God, prayed often, and had high levels of spirituality (e.g., finding meaning/peace in their lives and deriving comfort from faith). Thirty-five percent of adolescents reported praying once or more a day for symptom management. The most common positive R/S coping strategies used by adolescents were: "Asked forgiveness for my sins" (73% of surveys) and "Sought God's love and care" (73% of surveys). Most parents used R/S coping strategies to cope with their child's illness. R/S coping was not significantly associated with HRQOL ($p = NS$). R/S coping, particularly prayer, was relevant for adolescents with SCD and their parents. Future studies should assess adolescents' preferences for discussing R/S in the medical setting and whether R/S coping is related to HRQOL in larger samples.

Keywords

religiosity; coping; sickle cell disease; health-related quality of life

“...even though I have sickle cell I wake up and know I have my day on Earth...life expectancy is lower for people with sickle cell, but I just thank God that He woke me up this morning.” [13-year-old male]

Introduction

Sickle cell disease (SCD) is a chronic hematological disorder that affects nearly 1 out of every 500 African-Americans. Characterized by sickling of red blood cells, SCD can cause infections, anemia, organ failure, stroke, chronic lung disease, and thrombosis [1]. As a result, individuals with SCD experience unpredictable and recurrent episodes of pain [1]. Some children and adolescents with SCD have psychosocial difficulties, including lower self-esteem; higher levels of depression, anxiety, and behavior problems; impaired peer relationships; and repeated absences from school [2-4]. Thus, research that investigates potential ways to improve psychosocial adjustment to and coping with SCD is sorely needed.

Children and adolescents with chronic conditions, including those with SCD, face numerous medical and psychosocial challenges - all of which can have a significant impact on their health-related quality of life (HRQOL). A dynamic construct, HRQOL is used to describe functioning across multiple domains, including physical, psychological, and social functioning. Certain characteristics have been identified that promote adolescents' ability to successfully cope with or adapt to having a chronic illness [5]. These include: disease-related characteristics (e.g., severity, symptoms), personal characteristics (e.g., temperament, coping styles), and/or social-ecological characteristics (e.g., family functioning, social support).

Although patients' religion/spirituality (R/S) may play an important part in many dimensions of their lives, very little is known about how children may rely on R/S to cope with chronic illness [6,7]. Religiosity has been described as the formal, institutional, and outward expression of the sacred, such as church or temple attendance or frequency of prayer, whereas spirituality describes the internal and personal connections to the sacred (e.g., sense of meaning as it relates to the divine or the truth or the use of R/S to cope with personal adversity) [5]. Religious/spiritual coping focuses on how individuals may use R/S specifically to deal with a stressor such as a chronic illness. Like other coping mechanisms, R/S coping may represent both negative aspects (e.g., the extent to which someone feels that God is punishing them by giving them an illness) and positive aspects (e.g., the extent to which one derives spiritual support from a relationship with God or from a religious congregation).

A growing body of empirical evidence shows that R/S may have salutary effects on health outcomes, including adjusting to chronic illness [5-7]. Evidence suggests that adults who have higher levels of R/S recover from illness more quickly, are less depressed, and have better HRQOL than their counterparts with lower levels of R/S [5,8,9]. Similarly, adolescents who believe in God, rate religion as important in their lives, and attend religious services are less likely to engage in risky health behaviors and tend to have better mental health outcomes (i.e., less depression and anxiety) than their less religious peers [10,11]. The use of positive R/S coping strategies has been associated with improved physical and psychological health cross-sectionally in adult samples - whereas the use of negative R/S coping strategies correlated with poorer psychological and physical outcomes [9,12]. Because R/S has been shown to be an important part of adolescents' lives, it is surprising that such little attention has been paid to the role R/S may play in the adjustment and management of chronic illnesses [6,7]. Two preliminary studies of religious coping in pediatric samples, one in adolescents with asthma, and the other in children with cystic

fibrosis, suggest that religious coping is prevalent in these populations and may be associated with adjustment to the illness [6,7]. Of note, given that SCD disproportionately affects African-American adolescents, and given the particular importance of faith and R/S coping in the African-American community [5], it is especially important to examine the role of R/S in adolescents coping with an illness such as SCD.

Therefore, using a mixed method and multiple-informant approach, we sought to examine R/S in adolescents living with SCD and how they use R/S to cope with their illness. Given the critical role of parental coping in an adolescent's adjustment to living with a chronic illness, we also assessed the role of R/S coping in parents of adolescents with SCD. Finally, we examined the relationships between R/S coping and HRQOL outcomes in adolescents and their parents.

Methods

Participants and Procedures

This study was conducted during the 2007 and 2008 Sickle Cell Research and Education Day annual events held at Cincinnati Children's Hospital Medical Center (CCHMC) in Cincinnati, Ohio. Adolescents age 11-19 years with SCD were recruited via letter and flyer. During the 2007 Research and Education Day, eligible and interested adolescents were assigned to either a quantitative study protocol or a qualitative study protocol (see next section). At the 2008 annual event, only the quantitative questionnaire for the adolescent participants was administered. Parents/caregivers of all recruited adolescents were invited to complete a brief parallel parent survey in 2007 and 2008. Prior to participation, all eligible participants were briefed about the study and completed appropriate consent/assent forms. Adolescents were paid \$25 and parents \$35 for participating in the study. The study protocols were approved by the CCHMC Institutional Review Board.

Measures

Adolescent quantitative survey—We administered a 216-item survey to adolescents. Participants rated how religious and spiritual they were on two 4-point Likert scale with scores ranging from “not at all” to “very.” Importance of religion and belief in God were also assessed using a 4-point Likert scale with responses ranging from “strongly agree” to “strongly disagree.” Spirituality was examined using the Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp) Scale [13]. The FACIT-Sp is a 12-item measure that asks participants to indicate how true various statements are about them on a Likert scale of 0 (“not at all”) to 4 (“very much”). Responses on the FACIT-Sp are summed to create a total score, ranging from 0 to 48, with higher scores representing higher levels of spirituality.

Positive and negative R/S coping was assessed using the Brief RCOPE [14], a 14-item instrument. Responses on the Brief RCOPE indicate the frequency with which participants have used R/S coping behaviors on a Likert scale of 1 (“not at all”) to 4 (“a great deal.”) The outcome variable, HRQOL, was assessed using the PedsQL™ 4.0, a multidimensional measure of HRQOL in children and adolescents, shown to have good reliability ($\alpha = .70$) and validity in adolescent with SCD [15]. The 15-item scale assessed physical, emotional, social, and school functioning, with scores ranging from 0 to 100 and higher scores representing better HRQOL.

Adolescent qualitative interview—We also conducted a 20-30 minute semi-structured interview with adolescents with SCD which focused on R/S coping. The interview consisted of 18 questions developed by the investigators to assess what role, if any, R/S coping played

for adolescents with SCD. Adolescents were asked about the use of R/S coping both in general (“Can you tell me about a specific time when religious or spiritual beliefs influenced a decision you made?”), and in relation to living with SCD (“Do your religious/spiritual beliefs influence how you deal with having sickle cell disease? If so, in what ways?”). Adolescents were also asked to compare their R/S beliefs and practices to their parents’ (e.g., “How are your religious or spiritual beliefs and practices the same as your parents’?” “How are they different?”) The interviews were conducted in private rooms by trained graduate students and research assistants, audiotaped, and then transcribed.

Parent quantitative survey—A 73-item survey was administered to non-matched parents of adolescents with SCD. The survey included items/measures assessing religiosity (importance of religion, frequency of prayer), spirituality (FACIT-Sp; [13]), and R/S coping (Brief RCOPE; [14]). The R/S coping questions were asked in relation to “ways you have coped with your child’s SCD since s/he was diagnosed.” The outcome variable was parent-reported adolescent HRQOL, with scores ranging from 0 (worst) to 100 (best) HRQOL [16].

Analyses

In order to determine the importance of R/S and R/S coping for participants, frequencies, means, and distributions were assessed on the results from surveys (both adolescent and parent). Cronbach’s alphas were calculated to examine the internal consistency of the R/S measures in the two samples. We used *t*-tests to compare the frequency of use of positive and negative R/S coping strategies in adolescents versus non-matched parents. For the qualitative interviews, a content analysis was completed by four of the authors (SC, DG, YR, JH). Major themes were identified and discussed as a group until consensus was reached on common themes [17]. We also tabulated the number and type of responses to key questions (e.g., “Do your religious or spiritual beliefs influence how you handle living with sickle cell disease?”) to examine trends in responses. In order to examine the relationships between R/S coping, HRQOL, and demographic variables in adolescents, we conducted Pearson’s correlations and *t*-tests. All quantitative analyses were conducted in SPSS version 16.0 [18] and a $p < .05$ was used for significance testing.

Results

Importance of Religiosity and Spirituality

A total of 48 adolescents (37 quantitative surveys and 11 qualitative interviews) and 42 parents completed this study (Table 1). All invited parents participated, though some had multiple children with SCD at the event. All adolescents who completed the quantitative survey reported a belief in God/a Higher Power and all but one reported a religious affiliation. Twenty-two (59%) considered themselves “very” or “moderately” religious and 22 (59%) considered themselves “very” or “moderately” spiritual; adolescents who said they were spiritual also reported similar levels of religiosity (Table 2a). Twenty-four (64%) adolescents prayed at least once a week and 19 (51%) reported attending religious services at least once a week. Mean (SD) overall FACIT-Sp scores were relatively high (35.9 [7.9]), as were FACIT-Sp meaning/peace (24.4 [5.9]) and faith (11.5 [3.4]) scores.

R/S issues were also salient for the 11 adolescents who completed the qualitative interviews. All reported a belief in God and about half reported belonging to a church, although many could not name their church or denomination. In the interview, when asked if being religious or spiritual meant the same or different things, 5 (46%) adolescents said “the same,” 3 (27%) said “different,” and 3 (27%) said “don’t know.” Almost all of the adolescents said that they have the same R/S beliefs as their parents/guardians.

Parents/guardians of adolescents with SCD also reported generally high R/S levels. Thirty-two parents (76%) considered themselves “very” or “moderately” religious and 37 (88%) considered themselves “very” or “moderately” spiritual (Table 2b). All believed in God; 40 parents (95%) agreed or strongly agreed that religion was important to them; 9 (35%) meditated at least weekly; 33 (79%) prayed once a day during the last 30 days; and 25 (60%) attended religious services at least monthly.

Use of Religious/Spiritual Coping

In the quantitative interviews, adolescents generally reported greater use of positive R/S coping strategies (e.g., looked for a stronger connection with God/Higher Power; $M = 19.9$, $SD = 5.1$) than negative strategies (e.g., wondered what he/she did for God/a Higher Power to punish him/her; $M = 11.8$, $SD = 4.4$; Table 3a). The most common positive R/S coping strategies used “quite a bit” to “a great deal” by adolescents were: “Asked forgiveness for my sins” ($n = 27$ [73%]) and “Sought God’s love and care” ($n = 27$ [73%]). Most adolescents reported using a “collaborative” R/S coping style (e.g., pray to God/a Higher Power for symptom relief) as opposed to a “self-directed” coping style (e.g., relying on oneself for relief and management) or a “deferring” coping style (e.g., leaving it up to God/a Higher Power to heal) [14]. Of note, adolescents used significantly more negative R/S coping strategies than did non-matched parents, $t(76) = -2.01$, $p < .05$. When asked specifically about the use of R/S to cope with symptoms of SCD, 13 (37%) adolescents reported praying once or more daily, 9 (26%) prayed once to a few times a week, and 13 (37%) had either never prayed or had prayed only once for symptom management.

When asked about R/S coping in general in the interviews, adolescents also described religion as helping them make decisions about whether or not to engage in risky behaviors. Some described thinking “what God would think” [17-year-old male] when they faced risky behavior decisions. They saw God as an “authority” figure who would disapprove of their smoking or drinking. One adolescent described using religion as a distraction from arguing family members to help her cope with domestic stress.

When adolescents were asked in the interview whether they believed that their parents’ religious or spiritual beliefs influenced how they (the parents) dealt with SCD, many reported that their parents or grandparents prayed for symptom relief or to “ask God to make me go through it and make me strong and stuff” [17-year-old female]. For some, having their parent pray was particularly relevant: “...my mom, she prays about it [SCD] and that is why I don’t get sick that much” [15-year-old female].

In the parent surveys, most parents/guardians used positive R/S coping strategies to cope with their child’s illness. When asked the extent to which they had used various methods to cope with their child’s SCD, parents reported generally using positive R/S coping strategies more commonly than negative R/S strategies (Table 3b).

Associations with Health-Related Quality-of-Life

Bivariate analyses indicated that school functioning was positively associated with overall spirituality, FACIT-Sp scores ($r = .57$, $p < .01$), particularly faith/comfort in one’s religious beliefs ($r = .59$, $p < .001$). Neither positive nor negative R/S coping was associated with HRQOL in parents ($r = .00$ and $r = .21$, respectively, $p = \text{NS}$ for both) or in adolescents ($r = -.02$ and $r = .01$, respectively, $p = \text{NS}$ for both).

Discussion

The primary aim of this pilot study was to examine R/S and R/S coping in adolescents with SCD and their parents. Similar to healthy adolescents and adolescents with other chronic

illnesses [19], these adolescents reported high rates of religious attendance and belief in God, prayed often, and had high levels of spirituality (finding meaning/peace in their lives as well as deriving comfort from their faith). Akin to work done by Smith and colleagues on a large national sample of adolescents [20], two-thirds of the adolescents in our survey did not differentiate between being a “spiritual” person versus a “religious” person. Some researchers have argued that the distinction between the terms “religious” and “spiritual” is merely academic and not a reflection of real differences for lay people [21]; still others have advocated including both terms in health outcomes research, given their often differential predictive value on outcomes [22]. Our study suggests that, while for some adolescents those terms are interchangeable, for others they may mean different things - and still others are not sure if they are different. Given this, we recommend that future studies use both terms wherever possible (i.e., to investigate whether religious or spiritual constructs predict health outcomes differently) and that qualitative studies examine the ways adolescents use R/S terminology and the ways in which their cognitive, emotional, and spiritual development impacts their understanding of those terms.

R/S was also important for parents/guardians of adolescents with SCD. Similar to adults in the general population [23], most parents believed in God and prayed daily. And similar to the 11 adolescents with discordant concepts of “religious” and “spiritual,” 17 parents (40%) also had discordant concepts (e.g., 10 reported being both “very spiritual” and “moderately religious”). As with adolescents, this suggests that when interviewing or surveying parents of children with a chronic illness about R/S beliefs, it is worthwhile to ask about both religiosity and spirituality, as they may reflect different constructs (and potentially impact health outcomes differently).

We also examined whether adolescents with SCD and their parents used R/S coping. In dealing with SCD, adolescents and parents both reported using R/S coping, particularly prayer. Specifically, about two-thirds of adolescents said that R/S and prayer helped them cope with living with SCD, primarily as “distractors” from painful episodes. Many adolescents described a “collaborative” R/S coping style in which they relied on God for support and on prayer for symptom relief, and tried to see how God was “strengthening” them in such situations.

Our multi-method approach highlighted an interesting difference in the quantitative versus the qualitative interviews regarding the description/use of R/S coping. For example, in the surveys, adolescents reported having used positive R/S coping strategies at high rates, though most in the qualitative interviews were unable to describe how prayer or religion helped them. These findings are similar to those described by Smith and colleagues in a national sample of adolescents - who felt that religion was important, but were not sure exactly how or why [11].

Of particular interest was that adolescents as a group reported greater levels of negative R/S coping or “spiritual struggles” as compared with the parents as a group. Spiritual struggles have been associated with poor physical and psychological health outcomes in a variety of adult populations [12]. While there were no statistically significant relationships between negative R/S coping and HRQOL in this pilot study (likely due to small sample size), the high rate of negative R/S coping warrants attention. For example, 31% of adolescents “decided the Devil made this (SCD) happen,” and 36% “questioned God’s love” for them (“quite a bit” to “a great deal”). These statements could be interpreted in various ways -- as signs of religious dualism, magical thinking, or as expressions of a belief system that helps the adolescent explain things that happen in their world, for example, having an illness such as SCD. The presence of such spiritual struggles should be taken as a caution - as such struggles may be associated with poorer psychological and/or physical health outcomes. A

referral to a board certified chaplain, pastoral counselor, or other mental health care professional for a more in-depth assessment may be warranted to understand the effect of the spiritual struggle and how the beliefs may be impacting the adolescent's health. In addition, further questioning and qualitative research with adolescents is needed to clarify how they understand those concepts (e.g., what did you mean when you said 'the Devil made this [SCD] happen?') and the ways in which such beliefs impact their lives.

Our study had several limitations. First and foremost was sample size, which limited our ability to conduct multivariable analyses and to draw definitive conclusions regarding relationships between R/S coping versus outcomes in patients with SCD. The study also aggregated data collected at two annual SCD Research Day events a year apart, with different interviewers. Still, the strength of this data collection process was that we were able to capture many families with SCD who might not have participated in the study otherwise. Another notable limitation is the focus on just R/S coping - as there are many other types of coping strategies that people use to deal with a chronic illness [24].

Despite these limitations, important clinical conclusions can be drawn. R/S coping is clearly important for adolescents with SCD and their parents. Both groups reported praying and collaborating with God frequently to help manage SCD. The relatively high levels of spiritual struggles, especially by adolescents, raises the clinical issue of incorporating discussions of R/S coping as part of routine care for adolescents with SCD and their parents. Future research should assess how best to screen for spiritual struggles in a busy clinical setting and how to most efficiently triage patients to busy pastoral care or mental health providers.

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Table 1

Demographic variables stratified by sample

Variables	Adolescent Quantitative N = 37	Adolescent Quantitative N = 11	Parent Quantitative N = 42
Age, years , Mean (SD)	14.4 (2)	15.2 (2)	32.1 (9)
Female gender, N (%)	20 (54)	5 (46)	40 (95)
Ethnicity			
African-American, N (%)	36 (97)	11 (100)	41 (98)
Caucasian, N (%)	0 (0)	0 (0)	1 (2)
Highest Parental Education			
High school graduate or less, N (%)	9 (24)	6 (55)	20 (38)
Some college, N (%)	10 (27)	1 (9)	13 (31)
College graduate or more, N (%)	12 (32)	3 (27)	9 (21)
Religious Preference			
Protestant, N (%)	4 (11)	1 (9)	8 (19)
Baptist, N (%)	9 (24)	3 (27)	13 (31)
Presbyterian, N (%)	1 (3)	0 (0)	0 (0)
Pentecostal, N (%)	1 (3)	0 (0)	0 (0)
Catholic, N (%)	1 (3)	0 (0)	0 (0)
Other, N (%)			
Christian, N (%)	7 (19)	3 (27)	4 (10)
Seventh Day Adventist, N (%)	3 (8)	0 (0)	1 (2)
Nondenominational, N (%)	1 (3)	0 (0)	3 (7)
Pentecostal, N (%)	2 (5)	0 (0)	3 (7)
Apostolic, N (%)	1 (3)	0 (0)	0 (0)
None, N (%)	4 (11)	4 (36)	9 (21)

Note. Sub-headers under each religious affiliation category represent write-in responses.

Table 2a

Adolescent Self-Rated Religiousness and Spirituality

		To what extent do you consider yourself a spiritual person?			
		Very Spiritual	Moderately Spiritual	Slightly Spiritual	Not Spiritual at All
<i>To what extent do you consider yourself a religious person?</i>	Very Religious, N (%)	7 (19)	3 (8)	0 (0)	0 (0)
	Moderately Religious, N (%)	0 (0)	9 (24)	2 (5)	1 (3)
	Slightly Religious, N (%)	0 (0)	3 (8)	7 (19)	1 (3)
	Not Religious at All, N (%)	0 (0)	0 (0)	1 (3)	1 (3)

Parent Self-Rated Religiousness and Spirituality

Table 2b

		To what extent do you consider yourself a spiritual person?			
		Very Spiritual	Moderately Spiritual	Slightly Spiritual	Not Spiritual at All
<i>To what extent do you consider yourself a religious person?</i>	Very Religious, N (%)	8 (19)	0 (0)	0 (0)	0 (0)
	Moderately Religious, N (%)	10 (24)	13 (31)	1 (2)	0 (0)
	Slightly Religious, N (%)	1 (2)	3 (7)	3 (7)	0 (0)
	Not Religious at All, N (%)	1 (2)	1 (2)	0 (0)	1 (2)

Table 3a
Adolescent's Religious Coping Strategies

	Not at All	Somewhat	Quite a Bit	A Great Deal
Positive Coping				
Looked for a stronger connection with God/a Higher Power, N (%)	2 (6)	9 (25)	13 (36)	12 (33)
Sought God's/a Higher Power's love and care, N (%)	2 (6)	7 (19)	10 (28)	14 (47)
Sought help from God/a Higher Power in letting go of my anger, N (%)	4 (11)	14 (39)	10 (28)	8 (22)
Tried to put my plans into action together with God/a Higher Power, N (%)	3 (8)	12 (33)	12 (33)	9 (25)
Tried to see how God/a Higher Power might be trying to strengthen me in this situation, N (%)	2 (6)	13 (36)	7 (19)	13 (36)
Asked forgiveness for my sins, N (%)	3 (8)	6 (17)	13 (36)	14 (39)
Focused on religion to stop worrying about my problems, N (%)	8 (22)	12 (33)	7 (19)	9 (25)
Negative Coping				
Wondered whether God/a Higher Power had abandoned me, N (%)	27 (75)	8 (22)	1 (3)	0 (0)
Felt punished by God/a Higher Power for my lack of devotion, N (%)	22 (61)	6 (17)	6 (17)	2 (6)
Wondered what I did for God/a Higher Power to punish me, N (%)	20 (56)	9 (25)	4 (11)	3 (8)
Questioned God's/a Higher Power's love for me, N (%)	14 (39)	9 (25)	8 (22)	5 (14)
Wondered whether my church had abandoned me, N (%)	26 (72)	7 (19)	2 (6)	1 (3)
Decided the devil made this happen, N (%)	17 (47)	8 (22)	8 (22)	3 (8)
Question the power of God/a Higher Power, N (%)	23 (64)	5 (14)	4 (11)	4 (11)

Table 3b
Parent's Religious Coping Strategies

	Not at All	Somewhat	Quite a Bit	A Great Deal
Positive Coping				
Looked for a stronger connection with God/a Higher Power, N (%)	0 (0)	6 (14)	11 (26)	25 (56)
Sought God's/a Higher Power's love and care, N (%)	1 (2)	3 (7)	11 (26)	26 (62)
Sought help from God/a Higher Power in letting go of my anger, N (%)	5 (12)	12 (29)	11 (26)	12 (29)
Tried to put my plans into action together with God/a Higher Power, N (%)	0 (0)	13 (33)	13 (33)	13 (33)
Tried to see how God/a Higher Power might be trying to strengthen me in this situation, N (%)	3 (7)	10 (24)	12 (29)	17 (41)
Asked forgiveness for my sins, N (%)	2 (5)	9 (21)	14 (33)	17 (41)
Focused on religion to stop worrying about my problems, N (%)	7 (17)	11 (26)	9 (21)	15 (36)
Negative Coping				
Wondered whether God/a Higher Power had abandoned me, N (%)	30 (71)	8 (19)	2 (5)	2 (5)
Felt punished by God/a Higher Power for my lack of devotion, N (%)	27 (64)	8 (19)	2 (5)	5 (12)
Wondered what I did for God/a Higher Power to punish me, N (%)	29 (69)	8 (19)	1 (2)	4 (10)
Questioned God's/a Higher Power's love for me, N (%)	36 (86)	3 (7)	1 (2)	2 (5)
Wondered whether my church had abandoned me, N (%)	39 (93)	1 (2)	1 (2)	1 (2)
Decided the devil made this happen, N (%)	32 (76)	5 (12)	2 (5)	3 (7)
Question the power of God/a Higher Power, N (%)	36 (86)	1 (2)	1 (2)	4 (10)