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**Research Article**

# The role of religiosity and spirituality in coping with sickle cell disease clinical severity

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## ABSTRACT

**Objectives:** Religiosity and spirituality often play a role in managing chronic diseases. Sickle cell disease (SCD) is a genetic chronic disease associated with lifelong complications, but there is limited analysis of the potential impact of religiosity and spirituality on SCD. This study aims to analyze the association between constructs of religiosity and spirituality with health outcomes (disease severity, depression, and pain) in an SCD population ($n = 275$).

**Methods:** Data from the INSIGHTS Study (NCT02156102) were used for this analysis. The relationships between religious/spirituality measures (religious attendance, self-reported spirituality, religious saliency, coping, and support) and SCD outcomes (disease severity, depression, and pain scores) were analyzed through bivariate correlations and multivariable models. Models adjusted for different dimensions of religiosity and spirituality separately (Model 1) and all measures simultaneously (Model 2).

**Results:** In the bivariate analyses, we found a positive association between disease severity and spirituality ($P < .05$) and an inverse relationship between positive religious coping and depression ($P = .01$). In Model 1, which adjusted for individual measures separately, there was an association between SCD severity and spirituality ($\beta = 0.07$, $P < .001$) as well as with religious attendance ($\beta = 0.02$, $P < .01$). However, in the models that simultaneously adjusted for all the measures (Model 2), religious attendance was no longer associated with SCD severity ($\beta = 0.006$, $P > .05$), while the association with spirituality remained significant ($\beta = 0.05$, $P < .05$).

**Conclusions:** The observed associations between spirituality and disease severity among patients with SCD suggest that individuals with severe disease may beneficially use spirituality to cope with complications. Future research should rigorously evaluate this hypothesis.

**KEYWORDS:** sickle cell disease, religiosity, spirituality, disease severity, religious coping

## LAY SUMMARY

This study evaluates the relationship between religion, spirituality, and sickle cell disease (SCD) outcomes (disease severity, depression, and pain). As the role of religion and spirituality evolves in the United States, we see changes in the role of religious attendance in the lives of individuals living with SCD. We surveyed a population of 275 individuals living with SCD regarding their religious attendance and importance of spirituality to cope with disease. Recruitment for this study took place between June 2014 and February 2020. We found that greater self-identified spirituality was associated with worse SCD severity. We theorize that this indicates that individuals use spirituality to help them cope with more severe disease. We posit that the lack of association with religious attendance may illustrate the decrease in church attendance across the United States.

## INTRODUCTION

### Background

Sickle cell disease (SCD) is an inherited disorder of hemoglobin caused by a single point mutation in the beta-globin gene that is associated with acute and chronic complications affecting physical, psychosocial, and emotional health.[1,2] SCD presents with severe acute and chronic complications, such as painful vaso-occlusive episodes, ischemic stroke, acute chest

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syndrome, splenic infarction, and priapism.[1] The greatest SCD burden is in sub-Saharan Africa and India, however, this genetic condition also affects approximately 100 000 people living in the United States.[1] In the United States, SCD primarily affects African Americans; one in every 365 African American babies born will have SCD.[3,4] Life expectancy also varies greatly among different countries. In sub-Saharan Africa, it is estimated that 50%-90% of children with SCD will die before the age of 5.[3,5] In contrast, most people with SCD in high-income countries will live well beyond age 18, but their life expectancy may still be reduced by more than 30 years compared to those without SCD.[3,6] In a 2019 simulation modeling study, life expectancy for a US SCD cohort was estimated to be 54 years.[7] Whether in the United States or other countries, multiple genetic, social, behavioral, and environmental factors can markedly impact the trajectory of the disease.[1]

Religiosity and spirituality have emerged as widely used psychosocial factors that can have health-enhancing effects for a broad range of health outcomes.[8] There are limited research studies examining how religiosity and spirituality are mediators associated with positive SCD coping mechanisms and health outcomes among both adults and adolescents.[9-13] Other scholars have discussed the importance of religious rituals when coping with SCD and have highlighted decreased pain levels among those with higher church attendance.[14,15] Ultimately, there is a need for additional research to enhance scientific knowledge on the association between religiosity and especially, spirituality, with individual behavior and coping skills among adults living with SCD.

### *Spirituality and religiosity*

The concepts of spirituality and religiosity are often debated and somewhat challenging to define and measure.[16,17] In 2023, 70% of US adults viewed themselves as spiritual, nearly half indicated that they are both spiritual and religious, and 22% reported they were "spiritual, but not religious."[18] People have struggled for many years and continue to struggle with defining both spirituality and religiosity; these definitions vary vastly in the literature, and there is no one accepted best definition.[19] While recognizing that spirituality and religiosity are extremely difficult to define, for the purpose of this study, we define religiosity in "behavioral terms, including frequency of, or participation in, culturally based activities/practices (eg, prayer/meditation, attendance at services, reading religious texts, performance of rituals, etc.)."[20] We define spirituality in "emotional terms, often referring to feelings or experiences of awe, wonder, harmony, peace, or connectedness with the universe or a higher power."[20] Spirituality is less associated with established religious structures, and many people who are not religious may describe themselves as spiritual.[21] Some scholars contend that spirituality is an "appealing construct" because it connotes an intrinsic characteristic in personal experiential terms.[22] In summary, religiosity is the behavioral religious acts one may participate in, and spirituality is emotionally and experientially defined, only quantified by the individual.

### *Religion and spirituality and chronic diseases*

Prior research has found that religious coping and spirituality are associated with health outcomes. For instance, religious attendance and religiosity, among both younger and older adults, have been inversely related to depressive symptoms.[23,24] In a national probability study of African Americans it was shown, prospectively, that religious social support mediated the association between religious behaviors and lower levels of depressive symptoms and heavy drinking.[25]

Previous research has identified religiosity and spirituality as protective psychosocial factors for individuals living with chronic diseases. A study of men with prostate cancer found that intrinsic religiosity and spirituality were inversely related to depression.[26] Furthermore, individuals living with chronic kidney disease have used religiosity and spirituality to as a source of social support and hope in the face of their disease.[27] Studies have found health-enhancing effects of religious engagement across multiple faith traditions around the globe.[8] Not surprisingly, then, in African American communities religion has also been associated with improved risk factors and/or health outcomes. For example, in the Jackson Heart Study, higher levels of religiosity and spirituality were associated with intermediate/ideal cardiovascular health goals such as achieving ideal levels of physical activity and smoking levels.[28] Similarly, in a national study of African Americans, religious behaviors were associated with higher levels of consumption of fruits and vegetables and lower levels of alcohol use.[29] Religiosity and spirituality are also important factors in managing self-care activities. For example, in a study of African Americans with Type 2 diabetes, spiritual and religious beliefs, along with social support, were associated with better diabetes self-care activities, such as diet and foot care.[29,30]

Although there is a relationship between religion, spirituality, and many chronic diseases, few studies have investigated religiosity and SCD outcomes. A study of 50 SCD patients found that church attendance once a week or more were associated with the lowest levels of pain, while prayer/bible study and intrinsic religiosity were unrelated to pain.[14] A study of 95 adults with SCD found that even after adjustment for demographic variables and diagnostic factors, higher levels of positive religious coping were associated with fewer hospital admissions.[31] A study of 71 patients with SCD found that higher levels of spiritual well-being were associated with higher levels of life control, but not with the severity of pain.[32] Although depression is higher among adults with SCD, a review of studies published between 1988 and 2018 that explored the relationship between religiosity and depressive symptoms among persons with SCD found no studies that had examined the use of religiosity to cope with depression.[33] Finally, several studies have found that spirituality and religiosity are helpful coping mechanisms for adolescents and adults in managing their SCD.[10,15,33-36]

Thus, the constructs of spirituality and religiosity and their association with disease severity for adults living with SCD need further investigation. Importantly, many of the existing studies of the association between religiosity and spirituality with SCD outcomes were published more than ten years ago. As more Americans are adopting the idea that they are "spiritual, but not religious", the landscape of religiosity and

spirituality continues to change and evolve.[18] This change in identity among the general population warrants the need for updated research that reflects the relationship between religious coping and spirituality within the SCD population. This study aims to analyze the association between the constructs of religiosity and spirituality with disease severity and psychosocial outcomes for adults living with SCD.

## METHODS

### Study design and participants

The Insights into Microbiome and Environmental Contributions to Sickle Cell Disease and Leg Ulcers Study (INSIGHTS) (NCT02156102) is a cross-sectional study of 275 adults with SCD recruited between June 2014 and February 2020 from across the United States. Study participants were adults, age 18 or older, with no upper age limit, living with SCD. Study criteria included SCD genotype (HbSS, HbSC, Hb S$\beta^+$-thalassemia, and Hb S$\beta^0$-thalassemia) and excluded people who were sickle cell trait carriers. The INSIGHTS study examines the psychosocial, environmental, genetic, and clinical dimensions of disease variation in patients with SCD. Participants were recruited from social media, flyers in physician offices, advocacy groups, conferences, participation in previous sickle cell research studies, and the snowball method. Researchers employed several methods to ensure participants' confidentiality: their records were kept secure with password protected information and no identifying information was included in the study analyses. Each participant underwent clinical evaluation with a medical history and physical exam and completed an interviewer-administered psychosocial survey. Participants were given the option to complete all parts of the study in either English or Spanish. All participants consented to participation prior to enrollment and received compensation for research participation at the time of study completion. Study approval was obtained through the National Institutes of Health (NIH) Institutional Review Board for protocol NCT02156102 (approved May 16, 2014).

### Measures

Several measures (Table 1) were used to assess important clinical and psychosocial factors related to SCD. We used the Sebastiani *Disease severity* algorithm that predicts 5-year mortality risk for individuals with SCD.[37] Data entry was confirmed by 2 individuals. It was entered by the study coordinator with assistance from the study clinicians using the SCD Severity Measure. Scores are calculated using clinical and laboratory measures including, but not limited to, pain, blood pressure, hemoglobin genotype, and reticulocyte percentage. Higher scores indicate higher disease severity and higher mortality risk within 5 years. *Depression* was measured with the Beck Depression Inventory.[38] *Pain Assessments* were examined using the Adult Sickle Cell Quality of Life Measurement Information System, known as ASCQ-Me.[39] ASCQ-Me evaluates 3 types of sickle cell pain: the frequency of pain episodes, severity of pain episodes, and interference of pain.

*Religiosity* and *spirituality* are multidimensional constructs, thus a variety of religious and spiritual measures from the Brief Multidimensional Measure of Religiosity and Spirituality (BMMRS) were used to capture a holistic understanding of religiosity and spirituality.[40,41] *Self-defined spirituality* was measured on a 4-point Likert scale where individuals rated themselves from "not at all spiritual" to "very spiritual." *Religious attendance* was measured on a 7-point Likert scale answering the question, "How often do you go to religious services?" (from "never" to "attending more than once per week"). *Religious saliency* was measured on a 4-point Likert scale evaluating how often one carries religion over into other dealings in life ("not at all" to "a great deal"). *Religious meaning* was a 4-item measure on a 4-point Likert scale evaluating how much spiritual or religious beliefs give meaning to one's life, purpose, and peace of mind ("strongly disagree" to "strongly agree"). *Religious support* was a 2-item scale that measures the expected levels of support or disapproval from one's religious congregation. *Positive religious coping* was a 2-item measure that evaluates the positive impact of religion as a coping mechanism. *Negative religious coping* was a 2-item measure that evaluates the negative impact of religion as a coping mechanism. Detailed descriptions of each measurement can be found in Table 1.

### Statistical analysis

Descriptive statistics were calculated to assess the sex (male, female), race (American Indian/Alaska Native, Asian, Black/African American, Native Hawaiian/Other Pacific Islander, White, multiracial), ethnicity (Hispanic, Non-Hispanic), age, birthplace (US Born, born abroad), and current hydroxyurea use of the population. In addition, we used descriptive statistics to evaluate the religious attendance frequency, self-reported spirituality, and religious saliency of the population. We conducted bivariate analyses (simple Spearman correlation analyses) to examine correlations between the religious measures (religious attendance, self-reported spirituality, religious saliency, religious coping, and religious support) compared with disease severity, depression, and pain scores.

To more directly assess the strength of the relationship between clinical outcomes (eg, disease severity, pain and depression) and the religious measures (eg, religious attendance, spirituality, religious meaning, religious saliency, religious coping, and religious support), multivariate analyses were used in which we adjusted for possible confounders (eg, age, sex, birthplace, marital status, and education). Specifically, 2 multiple linear regression analyses models were used to examine the outcomes for the religious and spiritual measures while adjusting for the sociodemographic variables. The first model examined each religious and/or spiritual measure separately while adjusting for sociodemographic confounders. The second model included all the religious and/or spiritual measures simultaneously, while adjusting for all the sociodemographic variables. Missing data were treated using listwise deletion and regression diagnostics were performed to examine analytical validity (eg, homoskedasticity, residual distribution, multicollinearity). Complete data were available for 245 of the 275 study participants. We used RStudio: Integrated Development for R and SAS version 9.4 to conduct the statistical analyses. Statistical significance was determined at the $P < .05$ value. Rho values ($\rho$) from 0.2 to 0.3 were determined

**Table 1.** Various measures used to understand religiosity, spirituality, and psychosocial and clinical variables.

| Measure | Concept | Scale |
|---|---|---|
| **Sickle Cell Disease Severity Measure** | Severity of disease | 5-year mortality risk for individuals with SCD, scale 0 to 1 (higher score indicates higher disease severity) |
| **Beck Depression Inventory** | Mental health | Score from 0 to 63, higher score indicates higher depressive symptoms |
| **Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me)** | Pain assessments | Pain episode severity (0 to 22), Pain episode frequency (0 to 12), Pain interference (1 to 25); higher score indicates higher pain episode severity, higher frequency of pain episodes, or higher pain interference |
| **Religious coping adapted from the Brief Multidimensional Measure of Religiosity and Spirituality (BMMRS)** | Positive/negative religious coping | Four item index evaluates one's religious coping skills as being dependent on God or blaming God on a 6-point Likert scale ("a great deal" to "I don't believe in God") |
| **Religious support adapted from the BMMRS** | Positive/negative religious support | Four item index measures the expected levels of support or disapproval from one's religious congregation on a 4 point Likert scale ("a great deal" to "not at all") |
| **BMMRS items:** | Religious attendance | 1 item ("never" to "more than 1x per week") |
| "How often do you go to religious services?" | Spirituality | 1 item ("very spiritual" to "not at all spiritual") |
| "How spiritual would you say you are?" | Religious saliency | 1 item ("a great deal" to "not at all") |
| "How much do you try to carry religion over into other dealings in your life?" | | |
| **Religious meaning** | Religious and spiritual meaning | 1 item with 4 sub-concepts evaluating how much one's spiritual or religious beliefs give meaning to one's life and purpose ("strongly agree" to "strongly disagree") |

to be somewhat correlated and Rho values less than 0.2 that were statistically significant ($P < .05$) were noted as weakly associated.

## RESULTS

Complete descriptive statistics for the study population are included in Table 2. There were 275 study participants with an average age of 38.8 years (SD = 12.1). The gender and racial/ethnic distributions were 56.2% females with 89.6% identifying as non-Hispanic Black American, with 66.2% reporting a US birth, and 60.4% reporting currently using hyrdroxyurea. The average disease severity score was moderately high at 0.54 (SD = 0.24) on a scale of 0 to 1, and the average Beck Depression Inventory score was 10.9 (SD = 8.9). The majority of participants (81.3%) reported being moderately/very spiritual and 39.9% reported attending religious services at least once a week. We also found that high religious attendance is correlated with high spirituality (rho = 0.41, $P < .05$). Table 3 illustrates the Spearman correlations between religiosity and spirituality variables with disease severity, depression, and different pain measures (frequency, severity, interference).

### Religious attendance

In Table 3, the results for the simple Spearman correlations indicate that one's religious service attendance was weakly correlated with disease severity ($\rho = 0.22$, $P < .05$) but was not significantly correlated with pain episode severity level ($\rho = -0.071$, $P > .05$), pain interference ($\rho = -0.042$, $P > .05$), or pain episode frequency ($\rho = -0.027$, $P > .05$). There was a very weak, but significant inverse relationship ($\rho = -0.14$, $P < .05$) between religious attendance and depression. In the multivariable regression model, religious attendance was associated with disease severity ($\beta = 0.02$, $P < .01$) and inversely associated with depression in the separate model ($\beta = -0.61$, $P < .05$) (Table 4). However, in the combined regression model, it was not significantly associated with any of the health outcomes (disease severity, depression, pain episode frequency, pain episode severity, and pain interference).

### Spirituality

In bivariate analyses, self-reported spirituality was positively correlated with disease severity ($\rho = 0.29$, $P < .05$) and inversely correlated with depression ($\rho = -0.152$, $P < .05$), but it was not correlated with pain episode severity levels ($\rho = -0.064$, $P > .05$) or pain episode frequency ($\rho = 0.023$, $P > .05$). The relationship between spirituality and pain interference was very weak, but significant ($\rho = 0.124$, $P < .05$). In the first set of multivariable regression models (in which each religious and/or spiritual measure is considered one at a time), spirituality was significantly associated with disease severity ($\beta = 0.07$, $P < .001$), depression ($\beta = -1.51$, $P < .05$), and pain interference ($\beta = 0.81$, $P < .05$). In the combined regression model, the association between spirituality and disease severity remained significant ($\beta = 0.05$, $P = .02$) but was no longer significant for depression ($\beta = -0.46$, $P > .05$) or pain interference ($\beta = 0.66$, $P > .05$).

### Religious saliency

In the correlation analyses, religious saliency, defined as the likelihood to "carry religion over into all parts of life," was weakly but significantly positively correlated with disease severity ($\rho = 0.26$, $P < .05$). It was also positively correlated with the pain interference measure ($\rho = 0.13$, $P < .05$). Religious saliency was not correlated with pain episode

**Table 2.** Summary of participant characteristics ($N = 275$).

| Participant characteristics | *N* | % |
|---|---|---|
| **Sex** | | |
| Male | 120 | 43.6% |
| Female | 154 | 56.2% |
| **Birthplace** | | |
| US born | 180 | 66.2% |
| Not US born | 92 | 33.8% |
| **Race** | | |
| Black | 256 | 97.0% |
| White | 4 | 1.5% |
| American Indian or Alaska Native | 3 | 1.1% |
| Native Hawaiian or Other Pacific Islander | 1 | 0.4% |
| **Ethnicity** | | |
| Hispanic | 28 | 10.4% |
| Not Hispanic | 240 | 89.6% |
| **Currently using hydroxyurea** | | |
| Yes | 163 | 60.4% |
| No | 107 | 39.6% |
| **Spirituality** | | |
| Very spiritual | 119 | 43.6% |
| Moderately spiritual | 103 | 37.7% |
| Slightly spiritual | 36 | 13.2% |
| Not at all spiritual | 14 | 5.5% |
| **Religious attendance** | | |
| Several times a week | 47 | 17.2% |
| Once a week | 62 | 22.7% |
| 2-3 times a month | 24 | 8.8% |
| About once a month | 31 | 11.4% |
| Several times a year | 26 | 9.5% |
| About once or twice a year | 38 | 13.9% |
| Never | 45 | 16.5% |
| | Mean ± SD | Range |
| **Age** | 38.8 ± 12.03 | 19-71 |
| **Psychosocial and clinical measures** | | |
| Disease severity | 0.54 ± 0.24 | 0-1 |
| Beck depression score | 10.9 ± 8.90 | 0-63 |
| Pain episode severity score | 15.0 ± 4.22 | 0-22 |
| Pain interference score raw | 9.7 ± 5.13 | 1-25 |
| Pain episode frequency score | 6.8 ± 2.94 | 0-12 |
| Religious meaning score | 11.9 + 1.80 | 4-16 |
| Religious salience score | 3.45 + 1.42 | 1-5 |
| Positive religious coping | 9.9 + 2.63 | 2-12 |
| Negative religious coping | 4.9 + 1.76 | 2-12 |
| Positive congregational support | 4.9 + 2.22 | 1-8 |
| Negative congregational support | 1.9 + 1.47 | 1-9 |

severity ($\rho = -0.087$, $P > .05$), pain episode frequency ($\rho = 0.03$, $P > .05$), or depression scores ($\rho = -0.089$, $P > .05$). In the first multivariate regression model (each religion/spirituality variable considered separately), religious saliency was significantly associated with disease severity ($\beta = 0.04$, $P < .001$), depression ($\beta = -0.77$, $P < .05$), and pain interference ($\beta = 0.45$, $P < .05$). However, in the combined multivariable regression model, religious saliency was not significantly associated with any of the 5 health outcomes.

## Religious meaning

The religious meaning measure was very weakly correlated with disease severity ($\rho = 0.18$, $P < .05$), but not with depression ($\rho = -0.06$, $P > .05$), pain episode severity ($\rho = -0.01$, $P > .05$), pain interference ($\rho = 0.05$, $P > .05$), or pain episode frequency ($\rho = 0.01$, $P > .05$). In the separate multivariable models, religious meaning was no longer associated with disease severity ($\beta = 0.01$, $P > .05$) but was inversely associated with depression ($\beta = -0.65$, $P < .05$). In the adjusted and combined multivariable models, there was no association between religious meaning and any of the health outcomes.

## Religious coping

Positive religious coping had a very weak association with disease severity ($\rho = 0.18$, $P < .05$) and a very weak negative association with depression ($\rho = -0.17$, $P < .05$), but it was not correlated with any of the pain measures. In the separate multivariable model, positive religious coping was associated with disease severity ($\beta = 0.01$, $P < .05$) and depression ($\beta = -0.81$, $P < .001$). In the combined multivariable models, positive religious coping was no longer significantly associated with disease severity but remained inversely associated with depression ($\beta = -0.80$, $P < .05$) and was also inversely associated with pain episode frequency ($\beta = -0.24$, $P < .05$).

Negative religious coping was positively correlated with depression scores ($\rho = 0.251$, $P < .05$), but it was not associated with disease severity ($\rho = -0.09$, $P > .05$), pain episode severity ($\rho = -0.05$, $P > .05$), pain interference ($\rho = 0.101$, $P > .05$), or pain episode frequency ($\rho = 0.07$, $P > .05$). In both of the adjusted regression models, negative religious coping remained significantly associated with depression, such

**Table 3.** Spearman correlations of religious attendance, spirituality, saliency, meaning, coping, religious support, and disease outcomes.

| | Disease severity | Depression | Pain episode severity score | Pain interference score | Pain episode frequency |
|---|---|---|---|---|---|
| **Religious attendance** | **0.22** | −0.14 | −0.071 | −0.042 | −0.027 |
| | ***P* < .001** | *P* = .03 | *P* = .24 | *P* = .50 | *P* = .66 |
| **Spirituality** | **0.29** | **−0.152** | −0.064 | **0.124** | 0.023 |
| | ***P* < .0001** | ***P* = .013** | *P* = .29 | ***P* = .041** | *P* = .71 |
| **Religious saliency** | **0.26** | −0.089 | −0.087 | **0.13** | 0.030 |
| | ***P* < .0001** | *P* = .15 | *P* = .15 | ***P* = .03** | *P* = .62 |
| **Religious meaning** | **0.18** | −0.06 | −0.01 | 0.05 | 0.01 |
| | ***P* = .004** | *P* = .32 | *P* = .87 | *P* = .38 | *P* = .91 |
| **Positive religious coping** | **0.18** | **−0.167** | −0.006 | −0.002 | −0.097 |
| | ***P* = .004** | ***P* < .01** | *P* = .92 | *P* = .98 | *P* = .11 |
| **Negative religious coping** | −0.09 | **0.251** | 0.05 | 0.101 | 0.067 |
| | *P* = .16 | ***P* < .0001** | *P* = .42 | *P* = .10 | *P* = .28 |
| **Positive congregational support** | **0.17** | −0.073 | −0.118 | 0.007 | 0.070 |
| | ***P* = .007** | *P* = .24 | *P* = .06 | *P* = .91 | *P* = .26 |
| **Negative congregational support** | 0.03 | 0.104 | −0.094 | 0.086 | 0.036 |
| | *P* = .61 | *P* = .10 | *P* = .13 | *P* = .16 | *P* = .56 |

Significance determined at a level of $P < 0.05$.

**Table 4.** Regression models of religious and demographic variables with health outcomes (disease severity, depression, pain measures).

| | Model 1[a,b]: outcomes and parameters estimates | | | | | Model 2[a,c]: outcomes and parameter estimates | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Disease severity | Depression | Pain episode frequency | Pain episode severity | Pain interference | Disease severity | Depression | Pain episode frequency | Pain episode severity | Pain interference |
| Spirituality | 0.07*** | −1.51* | 0.22 | −0.39 | 0.81* | 0.05* | −0.46 | 0.19 | −0.38 | 0.66 |
| Religious attendance | 0.02** | −0.61* | 0.003 | −0.12 | −0.09 | 0.006 | −0.14 | −0.07 | −0.06 | −0.21 |
| Religious saliency | 0.04*** | −0.77* | 0.06 | −0.31 | 0.45* | 0.01 | −0.09 | 0.05 | −0.30 | 0.33 |
| Religious meaning | 0.01 | −0.65* | 0.03 | −0.001 | 0.09 | −0.01 | 0.44 | 0.20 | 0.002 | 0.14 |
| Positive religious coping | 0.01* | −0.81*** | −0.10 | 0.04 | −0.03 | −0.001 | −0.80* | −0.24* | 0.27 | −0.27 |
| Negative religious coping | −0.01 | 1.13*** | 0.03 | 0.09 | 0.12 | −0.01 | 1.39*** | −0.005 | 0.06 | 0.08 |
| Positive congregational support | 0.02** | −0.35 | 0.08 | −0.20 | 0.08 | 0.01 | −0.37 | 0.11 | −0.14 | 0.02 |
| Negative congregational support | 0.01 | 0.85* | 0.06 | −0.20 | 0.29 | −0.003 | 1.30** | 0.10 | 0.01 | 0.27 |

[a] All models control for age, sex, marital status (married vs not), birthplace (US born vs born abroad), education (eighth grade or below, high school graduate or equivalent, associates/technical/vocational degree, some college, bachelors degree, masters degree, professional degree, doctoral degree).
[b] Model 1: Separate models for each religious/spiritual measure with each outcome.
[c] Model 2: A single model including all of the religious/spiritual measures simultaneously.
* $P < .05$, ** $P < .01$, *** $P < .001$.

that for each unit increase in negative coping scores, the participant's Beck depression score would increase by 1.13 points ($P < .001$) in the separate regression model, and 1.39 points ($P < .001$) in the combined model.

### Religious support

Positive congregational support was very weakly associated with disease severity ($\rho = 0.17$, $P < .05$) but was not associated with depression ($\rho = -0.073$, $P > .05$), pain episode severity ($\rho = -0.118$, $P > .05$), pain episode frequency ($\rho = 0.07$, $P > .05$), or pain interference ($\rho = 0.007$, $P > .05$). In the separate regression models, positive congregational support remained significantly associated with disease severity ($\beta = 0.02$, $P < .01$) but was not associated with any of the health outcomes in the combined model.

Negative congregational support was not associated with disease severity ($\rho = 0.03$, $P > .05$), depression ($\rho = 0.104$, $P > .05$), pain episode severity ($\rho = -0.094$, $P > .05$), pain interference ($\rho = 0.086$, $P > .05$), or pain episode frequency ($\rho = 0.036$, $P > .05$). For negative congregational support, however, the results indicated a positive association for both regression models, such that for every unit increase in negative congregational support, the Beck depression scores increased by 0.84 points ($P < .05$) in the separate model and increased by 1.30 points ($P < .01$) in the combined model.

## DISCUSSION

In both regression models, we found that one's self-reported spirituality is positively correlated with disease severity, and positive religious coping is inversely associated with depression scores. In the combined regression model, positive religious coping is inversely associated with pain episode frequency. Unlike the lack of association identified in other studies, in our study, negative religious coping is positively associated with depression scores.[33] At the same time, negative religious coping is associated with an elevated mortality risk, as determined by the disease severity scores.[42] Finally, while negative congregational support did not demonstrate any significant association in the bivariate model, it was positively associated with depression scores in both adjusted regression models. The use of reliable and previously validated instruments to measure the multidimensionality of spiritualty and religiosity was vital in the development of this study. As such, the Brief Multidimensional Measure of Religiosity and Spirituality (BMMRS) was used to capture a holistic understanding of religiosity and spirituality.[40,41] Though these measures have been used in a variety of populations, including individuals with chronic conditions such as epilepsy and in studies which examined multinational perspectives, but they were not specifically created for populations with SCD.[43,44]

The findings demonstrate: (1) spirituality may provide coping support, guidance, and peace for individuals struggling with higher disease severity; (2) positive and negative religious coping can potentially play important roles in managing depressive symptomology among the SCD community; and (3) in contrast to other studies, pain (severity, interference, and/or frequency) was not associated with religious attendance, saliency, meaning, or spirituality.

As disease severity increases, the need to cope with the disease complications also increases. First, due to the relationship illustrated between higher spirituality and higher disease severity, we suspect that people who have more severe disease may rely more on their spirituality to cope with the severity or intensity of their complications. Research on prayer and health, for example, suggests that the frequency of prayer can be a marker for the severity of the challenges that the individual faces.[45] This was consistent across the initial Spearman correlation and further confirmed in the adjusted regression models. Similar to our conclusions, Cooper-Effa et al[32] found that spiritual well-being may help some patients when coping with SCD. Further, a systematic review by Pandarakutty and Arulappan[46] identified spirituality to be a key antecedent of

health-related quality of life among children and adolescents with SCD.

Although the relationships between religious attendance, meaning, saliency, and disease severity were initially significant, these associations were not found in the combined regression model. Perhaps for this particular SCD community, spirituality alone provides a sense of peace and well-being that is necessary for those who are coping with more severe disease. These findings may illustrate spirituality as a unique, yet related, concept in the construct of religiosity.

Although some understandings of religiosity and spirituality have considered the 2 synonymous or overlapping, the societal change in the United States may have pushed some to draw a distinction between these 2 measures in their declaration of themselves as "spiritual, but not religious."[17,47] This finding may help conceptualize religiosity and spirituality as overlapping, but nonetheless distinct concepts. The stronger correlation with disease severity and spirituality indicates that this distinction may also be important as we understand how religiosity and spirituality affect disease outcomes. Regarding church attendance, we recognize that age may play a factor in religious attendance. At a global level, young adults are much less likely to attend worship or prayer services than older adults.[48] This does not mean that young adults are not spiritual, and may help explain the relationship between spirituality and disease severity. The mean age of 38.8 (SD 12.1) represents a robust population of young adults that may prioritize individual spirituality as well as older adults who may prioritize a religious institution and religious attendance.

Second, positive and negative religious coping play important roles in the management of depressive symptoms. The relationship between positive religious coping and lower depression scores indicates that the SCD population's use of religious coping appears to help curtail potential depression. It is important to note that depression was not associated with religious attendance, meaning saliency or spirituality in the combined regression model. This is inconsistent with other studies evaluating depression and religious measures.[23] For example, among the chronic kidney disease population, those who are particularly spiritual and/or religious have a lower risk of suicide and fewer depressive symptoms.[27] Furthermore, a sense of meaning and peace were important spiritual factors in mediating depression in prostate cancer patients.[26]

The association between negative religious coping and negative congregational support and depression is to be expected. If one is experiencing depressive symptoms, they may also be quick to blame their religious congregation for providing negative support; the converse may also be true, one's tendency to blame their religious institution for feelings of judgment, shame, or lack of support may also be coupled with a higher tendency toward depression. It is also possible that higher levels of negative social interaction can exacerbate depressive symptoms. While acknowledging one's own ability to control their experiences, at least in part, we also recognize that one's interactions with their religious community may positively or negatively impact one's health outcomes. This relationship highlights the importance of religious communities and may also encourage providers to thoughtfully incorporate the patient's community in the implementation of their care.

Third, in contrast to other chronic disease studies, our study did not find a strong correlation between pain episode severity, pain episode frequency, and pain interference and the majority of the religious measures.[14] Though in contrast to our finding of disease severity being associated with spirituality, the insignificant association between pain episode frequency, severity, and pain interference may be due to the fairly healthy nature of our study population. Notably, there was initially a very weak relationship between pain interference and spirituality, but the combined adjusted regression analyses indicated that this was not significant after controlling for age and sex. We hypothesize this may be reflective of society's evolving definitions of religiosity and spirituality. Although religiosity and spirituality were previously associated with coping with pain, individuals living with SCD may now resort to other means to help modulate their pain experiences.

The combined regression model found a significant inverse relationship between pain episode frequency and positive religious coping, which was not significant in the initial bivariate analysis. Similar to the relationship with depression, people with SCD may use their religious community to help them cope with and experience less frequent pain episodes, but this correlation does not exist with pain episode severity or pain interference.

## Limitations

Although we adjusted for sociodemographic variables in our models, there were other factors that we could not account for that may affect the results of the study, such as religious affiliation or mental health co-morbidities. Study participants were evaluated at steady state, meaning they were not experiencing any acute exacerbations of their disease. Additionally, most traveled to participate in the study, thus we may be lacking data from individuals with limited mobility due to more clinically severe disease. Furthermore, disease severity or pain frequency may affect the ability to attend religious services and may have affected the outcomes of the study.

Additionally, the difficulty defining "spirituality" and "religiosity" limits the objective nature of the study. These concepts are challenging to measure, and each participant may interpret them differently. This makes conducting research surrounding these variables particularly difficult, but nonetheless important. Some scholars assert that spirituality must only be defined in terms of a "deeply religious" person, but we believe that as the patients' perspectives of spirituality and religiosity shift, their health care providers' and researchers' interpretation of the role of religion in coping with disease may also change.[49]

The nature of which data were captured was a limitation in this study in various ways. First, self-reported bias may be introduced due to the influence of social desireability. Specifically, participants may have responded to measures based on personal beliefs of what is acceptable or expected. In turn, this may not be a true representation of the general population. We acknowledge that birthplace may impact one's religion-based activities and coping mechanisms, and though we included an option to self-report birthplace, inconsistent responses limited our ability to further disaggregate this variable and include it in the analysis.

The cross-sectional nature of the study limits the ability to understand the clinical outcomes longitudinally and analyze how coping mechanisms and spirituality change with disease exacerbations and/or progression. Religiosity and spirituality can fluctuate over time and over the course of one's lived experience, emphasizing the need for longitudinal studies to capture the complexity of these concepts. The quantitative methodology used in this study limit our ability to capture the nuances and lived experiences of individuals with SCD and as such emphasizes the need for research that utilizes mixed-methodologies.

## CONCLUSION

Previous studies have found an association between religiosity and spirituality and SCD.[10,14,15] These associations highlight potential sources of coping and pain management and further indicate that spirituality and religiosity can influence health care utilization as well as the course of disease and the quality of life. However, these studies fail to distinguish between religiosity and spirituality. The association that we found with disease severity and spirituality (but not other religiosity measures) should encourage future research to further investigate spirituality and religiosity as 2 distinct, yet related concepts. The current religious and spiritual climate in the United States highlights the importance of disentangling how Americans are understanding religiosity and spirituality in research studies, as well as deepening our understanding of religiosity and spirituality and disease outcomes. Future research should also examine these same concepts and questions among sickle cell populations with diverse religious backgrounds, such as Muslim and traditional African religions.

This study found that spirituality may serve as a coping mechanism for those with more severe SCD. We also found that positive and negative religious coping are important concepts in the management of depression in the SCD population. Finally, although pain frequency is associated with positive religious coping, in this cohort, other pain variables are not associated with any religious or spiritual measures. Through this research, we expand the current understanding of religiosity and spirituality as related, yet potentially distinct concepts, that individuals with SCD may use in helping navigate their illness. Our research helps further call attention to the wide variety and complexity of psychosocial issues that impact one's SCD experience. Our findings echo the growing recognition within the health professions that healthcare providers need to be more aware of the impact of religious and spiritual beliefs on their patients' health and purposefully incorporate these beliefs and practices into a holistic approach in caring for their patients, including those living with SCD.[8]

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## AUTHOR CONTRIBUTIONS

Courtney A. Stewart (Conceptualization, Methodology), Khadijah E. Abdallah (Data curation, Formal analysis, Software), Ashley J. Buscetta (Conceptualization, Methodology), Hasmin C. Ramirez (Data curation, Formal analysis, Software), and David R. Williams (Conceptualization, Methodology), Vence L. Bonham (Conceptualization, Funding acquisition, Methodology, Project administration, Supervision)

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## CONFLICTS OF INTEREST

The authors have no relevant financial or non-financial interests to disclose.

## DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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