ABSTRACT

Sickle cell disease (SCD) is an inherited hemoglobinopathy that can evolve with time, in some individuals, as a debilitating chronic pain syndrome with emotional dysfunctions. Therefore, this study aimed to evaluate different types of religiosities: organizational (ORA), non-organizational (NORA), and intrinsic religiosity (IR), and their correlation with mental health in individuals with SCD. The variables analyzed were depression, anxiety, and catastrophic and suicidal thoughts. This is a descriptive cross-sectional study, which is part of a crossover randomized clinical trial. We recruited adults among individuals with SCD from Bahia-Brazil. We used: Duke’s religiosity index, Hospital Anxiety and Depression Scale (HADS), and Brazilian Portuguese Pain Catastrophizing Scale (BP-PCS) data. The Spearman correlation and Fisher exact test were used for statistics. Of the 131 individuals approached for participation, 75 completed all questionnaires with genotype HbSS and HbSC. Of them, 49 (65.3%) were women, with an average age of 34.13 ± 10.02, 66 (88.0%) self-declared black, 63 (84.0%) declared to

1 MsC, Graduate, Faculdade Adventista da Bahia, Adventist Neuromodulation and Neuroscience Laboratory, Bahia Adventist College, Cachoeira, Brazil; Escola Bahiana de Medicina e Saúde Pública.
2 PhD, Center of Mathematics, Computation and Cognition, Universidade Federal do ABC, Santo André, Brazil; NAPeN Network (Rede de Núcleos de Assistência e Pesquisa em Neuromodulação), Brazil.
3 Graduate, Adventist Neuromodulation and Neuroscience Laboratory, Bahia Adventist College, Cachoeira, Brazil.
4 MsC, Interdisciplinary Group for Studies and Research in Education, Religion and Health – GIEPERS, Bahia Adventist College, Cachoeira, Brazil.
5 PhD, Mathematics, and Cognition Center, Universidade Federal do ABC.
6 Ph.D., Applied Mathematics, Universidade de Trás-os-Montes e Alto Douro, Vila Real, Portugal.
7 PhD, Graduate, Research and Innovation. Escola Bahiana de Medicina e Saúde Pública.
belong to a religious group, 67 (89.3%) with a high form of religious involvement. The mean of intense pain was 3.86 ± 2.74; 40 (53.33%) had anxiety, 25 (33.33%) had depression, and 15 (20.0%) declared having suicidal thoughts. There was a negative correlation between depression and IR (r = -0.240, p = 0.038) and a correlation between average pain and NORA (r = 0.301, p = 0.009). An association between NORA and chronic pain was verified (p = 0.023), OR (p < 0.001), NORA (p = 0.042), and IR (p = 0.004) with evangelical SCD subjects. This study highlights the need for mental health care in patients with SCD due to the high rates of anxiety and depression, with the need to include religiosity since it is a frequent and important element in the lives of people with SCD.

KEYWORDS
Sickle Cell Disease; Religiosity; Depression; Anxiety; Mental Health.

RESUMO
A doença falciforme (DF) é uma hemoglobinopatia hereditária que pode evoluir com o tempo, em alguns indivíduos, como uma síndrome de dor crônica debilitante com disfunções emocionais. Portanto, este estudo teve como objetivo avaliar diferentes tipos de religiosidades: organizacional (ORA), não organizacional (NORA) e religiosidade intrínseca (RI), e sua correlação com a saúde mental em indivíduos com DF. As variáveis analisadas foram depressão, ansiedade e pensamentos catastróficos e suicidas. Trata-se de um estudo descritivo, transversal, que faz parte de um ensaio clínico randomizado cruzado. Recrutamos adultos com DF da Bahia-Brasil. Foram utilizados: índice de religiosidade de Duke, escala hospitalar de ansiedade e depressão (HADS) e dados da escala portuguesa de catastrofização da dor (BP-PCS). A correlação de Spearman e o teste exato de Fisher foram utilizados para estatística. Dos 131 indivíduos abordados para participação, 75 preencheram todos os questionários com genótipo HbSS e HbSC. Destes, 49 (65,3%) eram mulheres, com idade média de 34,13±10,02, 66 (88,0%) autodeclararam-se negros, 63 (84,0%) declararam pertencer a grupo religioso, 67 (89,3%) com uma elevada forma de envolvimento religioso. A média de dor intensa foi 3,86 ± 2,74; 40 (53,33%) apresentavam ansiedade, 25 (33,33%) apresentavam depressão e 15 (20,0%) declararam ter pensamentos suicidas. Houve correlação negativa entre depressão e RI (r = -0,240, p = 0,038) e correlação entre dor média e NORA (r = 0,301, p = 0,009). Foi verificada associação entre NORA e dor crônica (p = 0,023), OR (p < 0,001), NORA (p = 0,042) e RI (p = 0,004) com indivíduos evangélicos com DF. Este estudo destaca a necessidade de cuidados em saúde mental em pacientes com DF devido aos altos índices de ansiedade e depressão, com desejável atenção a religiosidade, por ser um elemento frequente e importante na vida das pessoas com DF.

PALAVRAS-CHAVE
Doença Falciforme; Religiosidade; Depressão; Ansiedade; Saúde Mental.
Introduction

Sickle cell disease (SCD) is an inherited hemoglobinopathy, were some individuals can evolve with time into a debilitating chronic pain syndrome\(^8\) 30-40% of adult patients\(^9\). SCD has characteristics that differentiate other chronic pain conditions, such as onset in early childhood, genetic disease, lifelong duration, and life-threatening\(^10\). SCD is Brazil’s most common hereditary monogenic disease, occurring predominantly among Afro descendants\(^11\).

Among the emotional dysfunctions\(^12\), depression more often than anxiety can be developed in individuals with sickle cell disease. Depression can be accompanied by suicidal thoughts or ideation\(^13\), which can be identified since adolescence\(^14\) because, in addition to the pain, social factors such as body image and mood swings are expected at this stage.

Spirituality and religiosity has been identified as a way of coping with chronic pain diseases\(^15\) and also for SCD\(^16\). Spirituality can improve quality of life\(^17\); is associated with fewer hospitalizations\(^18\); and a significant reduction in pain intensity\(^19\). Religion is configured as the search for spirituality through some religious institution. Since spirituality does not necessarily need a religion, it is a process where the importance of life is recognized as oriented to something intangible that is beyond or more prominent than themselves\(^20\).

The Duke University Religion Index (DUREL) has been used since 1995, assessing three religious dimensions relevant to the religious involvement in the life of a person, defined at a consensus meeting of the National Institute on Aging and the Fetzer Institute conference. As organizational religious activity (ORA), non-organizational religious activity (NORA), and

---


\(^13\) EDWARDS et al., 2009.


intrinsic or subjective religiosity (IR). The first, ORA, are public religious activities such as attending religious services or other group-related activities. The second dimension of NORA consists of religious activities performed in private, such as Scripture study, prayer, listening to the radio, or watching religious TV. The last IR assesses the degree of personal religious commitment or motivation that involves pursuing religion as an ultimate end\(^\text{21}\).

Therefore, this study aimed to investigate the associations and correlations of different types of religiosities (organizational, non-organizational, and intrinsic) in individuals with SCD with mental health variables such as depression, anxiety, and catastrophic and suicidal thoughts.

**MATERIALS AND METHODS**

**Study design, setting, and participant’s description**

This descriptive cross-sectional study is part of a crossover randomized clinical trial registered in REBEC n. TN: U1111-1243-3020, already published\(^\text{22}\), with adult individuals diagnosed with Sickle Cell Disease. All SCD individuals were recruited between October 2019 and May 2022 in the Basic Health Center (BHC), from cities in the Recôncavo Baiano, in the 31st health region of Bahia (DIRES-BA), and the association of sickle cell disease of the city of Feira de Santana-BA. All SCD individuals received an explanation about the collection data procedures, signed the informed consent form, and voluntarily agreed to participate in this study following Resolution 466/2012 of the National Health Council of Brazil. This study was approved by the Ethics and Research Committee of Faculdade Adventista da Bahia\(^\text{23}\).

The Inclusion criteria were having a sickle cell disease diagnosis and being over 18 years of age. The Exclusion criteria were the history of hospitalizations for painful crises in the last 15 days and being more than 50 years old (because of the primary crossover study exclusion criteria). The process of contact with sickle cell disease carriers occurred in two ways (figure 1). The sample was for convenience. All adults who attended the interview site or who visited and agreed to participate were included in this research. One adequately trained researcher applied the questionnaires.


\(^{23}\) CAAE No. 94835218.8.00000.0042.
Procedures

The SCD participants were invited to undergo screening at their local Basic Health Center or their homes. The sociodemographic questionnaire gathers information on age, gender, education level, marital status, race, religion, and pain levels.

Outcomes and assessment procedures

Level of Religiosity

Duke’s religiosity index is a five-item scale measuring three dimensions of religious involvement related to health outcomes: Organizational religiosity (ORA) (i.e., frequency of church attendance); non-organizational religiosity (NORA) (i.e., utilization of private religiosity as prayer or Bible study); and intrinsic religiosity (IR) (i.e., experiencing the presence of the divine, allowing religious beliefs to guide an approach to life, and transporting religion into other areas of life). It is recommended that the values are not summed but analyzed separately24.

Pain Intensity

Pain intensity measures were assessed by the Visual Analog Scale (VAS), which ranges from zero to 10, where zero represents no pain and 10 is the worst imaginable pain. A high score represents a high pain intensity or pain interference.

---

Symptoms of anxiety and depression

Symptoms of anxiety and depression were assessed with the Hospital Anxiety and Depression Scale (HADS), which comprises 14 self-reported questions divided into two subscales: one for anxiety and the other for depression. The subject will rate each item using an ordinal scale varying from zero (non-existent symptom) to three (very severe symptom)

Brazilian Portuguese Pain Catastrophizing Scale (BP-PCS)

The BP-PCS questionnaire consists of 13 items evaluating self-reported catastrophizing thoughts, feelings, and behaviors when in pain. It is divided into three domains: helplessness, magnification, and rumination. Items are rated on a 5-point Likert-type scale in which both intensity and frequency information are represented, with the following five levels of response for each item: (0) not at all, (1) to a slight degree, (3) to a moderate degree, (4) to a great degree, (5) and all the time. The PCS total score ranges from 0 to 52 points.

Avoid record bias

To avoid interviewer bias, only one researcher applied all the questionnaires. All questions were read to avoid comprehension difficulties. There was no contact between the participants. Before applying the questionnaires, everyone was asked if he felt able to answer several questions for 30 to 40 minutes, questions that even covered his emotional state. To control pain measurement bias, medication use was recorded.

Statistical analyses

Data were organized in spreadsheets and analyzed using Statistical Package for the Social Sciences (SPSS) v20.0, and the normality distribution was assessed by the Shapiro-Wilk test. The sample characterization of the demographic and clinical variables was analyzed by Chi-square or Fisher’s Exact tests when comparing the frequency distributions and Mann-Whitney or independent Student-t tests when comparing the averages or median. The variables ORA, NORA, and IR were associated and correlated with the variables sociodemographic characteristics (age, sex, civil status, educational level, and financial government aid) and clinical characteristics (pain intensity, depression, anxiety, catastrophic and suicidal thoughts) using Chi-square or Fisher’s Exact, and Spearman tests according to respective statistics assumptions. Therefore, the association the religious types and pain and clinical outcomes in individuals with SCD were tested. In all statistical tests, the significance level alpha 5%, and the Beta of 80%.

RESULTS

Sociodemographic and illness-related characteristics:

Of the 131 individuals approached for participation in this study, 80 consented to participate, five were ruled out for having traits, and 75 completed all questionnaires. Those who refused to participate indicated a lack of time or interest in participating in a survey (Flow chart 1).

Flow chart 1. Number of participants

Seventy-five adults diagnosed with SCD, identified in primary health centers in six cities in the Bahian Recôncavo, participated in this study. The participants had HbSS and HbSC genotypes, 49 women and 26 men. The average age was 34.13 ± 10.02. With mean pain 3.86 ± 2.74(SD) on the visual analog scale (VAS). Of these, 66 (88.0%) declared themselves as black, eight (10.7%) declared themselves as brown, and one (1.3%) declared themselves as white. The average subject’s financial income was less than the country’s minimum wage, established at US$ 242.40. See table 1.
A total of 40 (53.33%) individuals had anxiety, and 25 (33.33%) had depression. Twenty-three (30.66%) of the subjects tended to have anxiety and depression associated. Only two subjects (2.6%) declared a suicide attempt, and 20% declared having or having had suicidal thoughts; however, there was no association or correlation between belonging to a religious organization or any type of religiosity with ideation or attempt to commit suicide.

**Correlations between types of religiosities (organizational, non-organizational, and intrinsic) and the illness-related variables and other study measures:**

This study showed a high percentage of individuals who declared that they belonged to a religious group (84.0%), with intrinsic religiosity being the most frequent form of religious involvement (89.3%), with no significant differences between the sexes. The correlation between religious types and catastrophism, HADS anxiety, HADS depression, and average pain was analyzed by Spearman’s test (Table 2). This group of adults with SCD showed a weak negative correlation between depression and intrinsic religiosity (r = -0.240, p = 0.038). A correlation between average pain and non-organizational religion was also identified (r = 0.301, p = 0.009).
Table 2. Correlation between types of religiosity and variables evaluated in the study.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Organizational Religion</th>
<th>Non-Org Religion</th>
<th>Intrinsic Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catastrophism</td>
<td>r = 0.133 (p = 0.256)</td>
<td>r = 0.112 (p = 0.339)</td>
<td>r = 0.141 (p = 0.228)</td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>r = 0.003 (p = 0.982)</td>
<td>r = 0.056 (p = 0.633)</td>
<td>r = -0.023 (p = 0.845)</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>r = 0.031 (p = 0.795)</td>
<td>r = 0.001 (p = 0.990)</td>
<td>r = -0.240 (p = 0.038)</td>
</tr>
<tr>
<td>Average Pain</td>
<td>r = 0.199 (p = 0.088)</td>
<td>r = 0.301 (p = 0.009)</td>
<td>r = 0.080 (p = 0.498)</td>
</tr>
</tbody>
</table>

Correlation is significant at the 0.05 level (2-tailed).

Fisher’s exact test was used to assess the association between types of religiosity and the presence or absence of chronic pain. We found a significant association between NORA and chronic pain (p = 0.023). The association between the type of religion and adults self-called: Catholic, Evangelical, and non-religious was analyzed using Fisher’s exact test. There was a significant association between self-declared Evangelical (protestant and neo-pentecostal) adults and ORA (p < 0.001 – two-tailed p-value); NORA (p = 0.042 – two-tailed p-value); and IR (p = 0.004 – two-tailed p-value).

Fisher’s exact test was used to determine whether there was any association between the level of education and religiosity. There was a significant association between studying in high school (or have stopped at this level) with IR (p = 0.032 – two-tailed p-value) and NORA (p = 0.012 – two-tailed p-value). The mean age of these individuals was 32.75 years old (9.76 SD).

Fisher’s exact test was used to determine whether there was a significant association between type of religiosity and marital status. There was a statistically significant association between IR and married subjects (p = 0.014 – two-tailed p-value). There was also an association between ORA and married marital status (p = 0.006 – two-tailed p-value).

It was analyzed if there was an association between type of religion and adults with SCD who received or did not receive a government financial benefit related to their disease. There was a significant association between adults with SCD who did not receive government benefits with NORA (p = 0.016 – two-tailed p-value); and a significant association of these same subjects with IR (p = 0.043 – two-tailed p-value).

**DISCUSSION**

Our population showed high levels of religiosity compared to previous studies and higher levels of IR. Intrinsic religiosity refers to feeling the presence of the Holy, that religious belief is

---

behind the way of life, and finally, that there is an effort by the individual to live their religious beliefs in all aspects of life.

It is questionable the fact that none of the interviewees declared a religion with African roots, since Umbanda is the most practiced African religion in Bahia, we believe that this can be explained by the African-American syncretism between religious practices with African roots and Catholicism. Therefore, we do not rule out that people who declare themselves Catholic can practice an African-based religion. Religiosity was associated with less pain in individuals with sickle cell disease, but not in our study.

There was a correlation between Average Pain and NORA. The greater the average pain, the greater the NORA, and an association between the presence of chronic pain and again NORA, defined as individual religious activities such as prayers, meditations, and reading the Bible or other biblical texts in their domicile. These individuals with a religious background may tend to religious practice, looking for relief from their pain and comfort, as described as a coping strategy.

The subjects of this study showed levels of depression, as the literature demonstrates for individuals with SCD, three times higher than the frequency of depression among the northeastern Brazilian population, where the study was carried out. However, anxiety levels are much higher (53.33% in our sample) than in the literature. In pain in Sickle Cell Epidemiology Study (PiSCEES Project), anxiety was 6.5%. This same study showed that anxiety and depression predict more significant daily pain and poor physical and mental quality of life. However, the study carried out with individuals with SCD, in the state of Bahia-Brazil, the percentages of depression and anxiety were even higher, because they specifically looked for people with pain of neuropathic origin.

For suicidal thoughts, our study showed 20% of participants were affected, which was between the average already exposed in the literature, with 10% identified in 2014 and 29% identified in 2009 and only 2.6% declared suicide attempt. Maybe this percentage relates to the high level of religiosity since some study correlates religion as a protective factor for suicidal thoughts. SCD in Bahia-Brazil, where this research was carried out, is a public health problem. However, there is no program aimed at this population for its monitoring and prevention of mental health.

References

30 COOPER-EFFA et al., 2001; GOMES et al., 2019.
31 EDWARDS et al., 2009.
33 LEVENDORN et al., 2008.
Our study observed a negative correlation between IR and depression. In other words, a higher frequency of intrinsic religiosity is associated with a lower frequency of depressive symptoms, and the opposite is true. The greater the tendency to depression, the less the feeling of the presence of God or the Holy Spirit, the less the truth that religious beliefs are behind the whole way of living, and the less the effort to live religion in all aspects of life. The apparent symptoms of depression, such as apathy, guilt, general discontent, hopelessness, mood swings, and loss of interest, can explain this. The literature states a positive relationship between mental health and religiosity. The frequent seclusion of individuals with depression may explain decreased social activities, less attendance at church, and fewer religious practices.

There was a significant correlation between Protestants (and neo-evangelicals) compared to Catholics and individuals who did not declare religion, with all types of religiosity (NORA, IR, and ORA). The literature recognizes that protestant and neo-evangelical adults practice their religion more than catholics, who call themselves non-practicing catholics. ORA and IR showed a correlation with married individuals; as pointed out by other studies, married individuals place religiosity at the center of their lives, compared to singles; married couples with and without children have more frequency to church than singles.

Our study showed a correlation between intrinsic and non-organizational religiosity among individuals who stopped their studies in high school. The average age of these individuals proved to be outside the study age, so it can be concluded that most of these individuals dropped out of high school or did not continue their studies; most of the subjects were in their late twenties and early thirties. The average monthly income of the research participants was mostly the Brazilian minimum wage. Low income in the population with SCD, may motivate the spiritual search.

Our study has some limitations. First, the sample size calculation was not performed because it is an exploratory study carried out with a convenience sample. The sample size may have needed to be increased to show the differences not observed between the groups. Furthermore, as this is a sample from a rural region, the data obtained cannot be extrapolated to other samples of people with sickle cell disease living in large metropolises. Nor can they be extrapolated to other populations, requiring the development of new studies testing our hypotheses in other populations and samples.

40 BRAAM; KOENIG, 2019; MURAKAMI & CAMPOS, 2012.
CONCLUSION

Among the main conclusions, we highlight that in our study, the population studied predominantly reported having a religious profile and experiencing their religiosity, demonstrating that the “sacred” has a recurring role in the lives of these patients affected by sickle cell disease. In other words, religiosity is a frequent and important element in the lives of people with SCD, as demonstrated by the high levels of organizational religiosity and intrinsic religiosity of our population. And although the benefit of religiosity in promoting, maintaining, and recovering health is consolidated, this understanding seems limited to other important variables and health outcomes in specific populations, such as those affected by sickle cell disease.

We infer that multidimensional studies are desirable that include the religious and spiritual dimension, even considering communities of faith, evaluating the profile and association of these dimensions and spaces in health outcomes in specific populations, as undertaken in this study. It should be noted that religious traditions have health hermeneutics when interpreting illness and death with different religious reasons, sometimes conflicting, sometimes cooperative with health sciences. Investigations, such as the one carried out in this article, can contribute to discussions that aim to expand these religious hermeneutics, including scientific knowledge in the health area, aiming at cooperation for the interests of the common good of civil society.

This study highlights the need for mental health care in patients with SCD due to high rates of anxiety and depression. Health professionals and other interested parties are invited to understand the specific types of religion and their participation in the lives of patients with SCD to define treatment with a holistic and multifactorial view. The state of Bahia needs a program to monitor and prevent the mental health of these individuals.

References


Submetido em: 20/06/2023
Aprovado em: 17/11/2023