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"Waiting for a miracle": Spirituality/Religiosity in coping with sickle cell disease

"À espera de um milagre": espiritualidade/religiosidade no enfrentamento da doença falciforme

"Esperando un milagro": Espiritualidad/Religiosidad en el afrontamiento de la enfermedad de célula falciforme

Maiara Vitor Gomes[I]
ORCID: 0000-0001-8487-6744

Aline da Silva Gomes Xavier[I]
ORCID: 0000-0002-3012-6849

Evanilda Souza de Santana Carvalho[I]
ORCID: 0000-0003-4564-0768

Rosa Cândida Cordeiro[II]
ORCID: 0000-0002-3912-1569

Sílvia Lúcia Ferreira[III]
ORCID: 0000-0003-1260-1623

Amarry Dantas Morbeck[I]
ORCID: 0000-0002-4847-1771

[I] *Universidade Estadual de Feira de Santana. Feira de Santana, Bahia, Brazil.*
[II] *Universidade Federal do Recôncavo da Bahia. Cruz das Almas, Bahia, Brazil.*
[III] *Universidade Federal da Bahia. Salvador, Bahia, Brazil.*

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Corresponding Author:
Aline Silva Gomes Xavier
E-mail: alinesgomes21@gmail.com

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ABSTRACT

Objective: To understand spirituality/religiosity as experienced by people with sickle cell disease, and its influence on coping with the disease. **Method:** A qualitative, descriptive, and exploratory study conducted in the State of Bahia. Twenty-nine respondents participated in semi-structured interviews. Content analysis was used to analyze the empirical material. **Results:** Individuals with sickle cell disease experience spirituality/religiosity motivated by their hope for a miracle, and fear of death; among their rites are: reading religious materials, individual and group prayer, and attendance at worship services. The effects on their health include: comfort by means of coping by comparing two evils, anxiety relief, social support, and lifestyle changes; however, spirituality/religiosity may be impaired. **Final considerations**: This study demonstrates the need to qualify health professionals to address spiritual issues of these individuals during illness, with the aims of diagnosing suffering and anguish, and providing care, comfort and strengthening of the spiritual bonds of these individuals.

Descriptors: Anemia, Sickle Cell; Spirituality; Pain; Holistic Nursing; Nursing Care.

RESUMO

Objetivo: Compreender a Espiritualidade/Religiosidade vivenciadas por pessoas com doença falciforme e sua influência sobre o enfrentamento da doença. **Método:** Estudo qualitativo, descritivo, exploratório, realizado no Estado da Bahia. Participaram 29 pessoas que responderam a entrevistas semiestruturadas. O material empírico foi submetido a análise de conteúdo. **Resultados:** Pessoas com doença falciforme vivenciam a Espiritualidade/Religiosidade motivadas pela esperança de um milagre e por medo da morte; seus ritos são as leituras de textos religiosos, orações individuais e em grupo, e frequência a cultos; os efeitos sobre sua saúde são: conforto através do *coping* de comparação, alívio da ansiedade, apoio social, mudança no estilo de vida, porém a Espiritualidade/Religiosidade podem manifestar-se prejudicadas. **Considerações finais:** Este estudo ressalta a necessidade da qualificação dos profissionais de saúde para a abordagem das questões espirituais dessas pessoas adoecidas, com a preocupação de diagnosticar possíveis sofrimentos, angústias e assim prestar auxílio, conforto e fortalecer os vínculos espirituais desses indivíduos.

Descritores: Anemia Falciforme; Espiritualidade; Dor; Enfermagem Holística; Cuidados de Enfermagem.

RESUMEN

Objetivo: Entender la espiritualidad / religiosidad como la experimentan las personas con enfermedad de células falciformes y su influencia en el afrontamiento de la enfermedad. **Método:** Un estudio cualitativo, descriptivo y exploratorio realizado en el estado de Bahía. Veintinueve encuestados participaron en entrevistas semiestructuradas. Se utilizó análisis de contenido para analizar el material empírico. **Resultados:** Las personas con enfermedad de células falciformes experimentan espiritualidad / religiosidad motivadas por su esperanza de un milagro y el miedo a la muerte; entre sus ritos se encuentran: lectura de materiales religiosos, oración individual y grupal, y asistencia a los servicios de adoración. Los efectos en su salud incluyen: comodidad mediante el manejo del afrontamiento, alivio de la ansiedad, apoyo social y cambios en el estilo de vida; sin embargo, la espiritualidad / religiosidad puede verse afectada. **Consideraciones finales:** Este estudio demuestra la necesidad de preparar a los profesionales de la salud para abordar los problemas espirituales de estos individuos durante la enfermedad, con el objetivo de diagnosticar el sufrimiento y la angustia, y de brindar atención, comodidad y fortalecimiento de los vínculos espirituales de estos individuos.

Descriptores: Anemia de Células Falciformes; Espiritualidad; Dolor; Enfermería Holística; Atención de Enfermería.

INTRODUCTION

Religion and science were in conflict for a long time, culminating in the dissociation of these two practices. From the scientific revolution of the sixteenth century, diseases began to be explained only with a physical-biological focus, disregarding psychological, social, and spiritual aspects[1] in the processes of suffering.

However, in recent times it is possible to notice changes, with a growing appreciation of the psychological and spiritual demands of individuals, which can be evidenced by an increase in the number of religions, the daily demands of people in their daily lives, and, consequently, the search for the meaning of life in such a dynamic and unstable world[2].

Awareness of the rise in spiritual demands in people's lives, and the importance of this human dimension for complete treatment, led the World Health Organization to include, in 1988, the spiritual dimension in the multidimensional concept of health, referring to questions of significance and meaning of life, without restricting it to any specific type of belief or religious practice[3]. With this reality, the psychological and spiritual aspects receive more value, in combination with the physical treatments and medications.

Spirituality/Religiosity (S/R) refers to the relationship of the person with the transcendent in the search for the meaning of life. However, although they seem to be synonymous, these terms are differentiated by their comprehensiveness; religion is characterized as a means of seeking spirituality through an organized religious institution, whereas spirituality does not require linkage to a religion, but is inherent in the individual[4].

Spirituality, from the Latin *spiritus* (meaning "breath," in reference to the breath of life), involves gratitude, development of the ability to see the sacred in common things. Religion, *religare*, means to reconnect and establish the connection between God and men. Thus, religiosity refers to behaviors and beliefs that are associated with religion[5-6].

The relationship between Spirituality/Religiosity and illness occurs, mainly, as a consequence of the suffering inherent in chronic illness, which promotes the search for inner strength to face the changes and adversities imposed by the disease, so that both spirituality and religiosity are accessed by ill individuals and their families, to overcome suffering in the health and illness process[7-8].

The literature has pointed to an increase in scientific production that evidences the appreciation of spiritual aspects, demonstrating a positive relationship between S/R and coping with illness. Studies demonstrate that higher levels of involvement with religion are positively associated with indicators of psychological well-being, and with less depression, suicidal ideation and behaviors, and drug and alcohol abuse[7,9-11].

Spirituality/Religiosity can act as a type of care for health and illness processes among individuals with chronic diseases, such as Sickle Cell Disease (SCD). A hereditary disease of high prevalence in the world, SCD affects hemoglobin (Hb), resulting in an abnormal hemoglobin called S (HbS), which causes polymerization of HbS with consequent deformation of sickle-shaped red blood cells. As they become more rigid, they cause a phenomenon of vascular obstruction, episodes of pain, injury of various organs, and visible bodily changes[12-13].

As the body is a social reflex, it is illogical to exclusively attribute its experiences to biological processes, since its behavior symbolizes a relationship with the world, with itself, and with others. The body changes caused by SCD negatively influence the patients' self-image, which can lead to serious psychological illnesses, such as depression and suicidal ideation, especially during painful crises[13].

The nursing team plays an important role in the care of people with SCD, because its members stimulate self-care by means of health education aimed at the empowerment of these individuals, identify and develop therapies to manage symptoms, act to manage and relieve pain, and adopt an integral idea about people with SCD[13]. However, in order to adopt a welcoming attitude towards those who suffer with chronic illnesses, nurses need to know and understand the beliefs, representations, and practices adopted by patients in search for relief from their suffering. Based on the above, this article was developed to answer the following questions: How do people with SCD experience S/R, and how do these experiences influence them in coping with the disease?

Repercussions of SCD on people's lives range from the difficulties in maintaining attendance at school, due to constant hospitalizations and periods of pain exacerbation, to discrimination in the family, employment environment, and health services in adult life. It is essential to understand the pathophysiological process of SCD, as well as its consequences in the different human dimensions of affected patients. When exploring the S/R of individuals with SCD, this study is justified because the disease with which the person lives from childhood, with severe pain, adds complications throughout life, requires strategies that complement or overcome intervention on the physical body to tolerate the resulting pain, limitations, and suffering. Thus, it can contribute to knowledge construction about the experience of individuals with SCD, to favor the understanding of health professionals, and to reflect on the planning of care, considering the multidimensionality of the human being.

OBJECTIVE

To understand S/R experienced by individuals with SCD, and their influence on coping with the disease.

METHOD

Ethical aspects

This study was approved by the Ethics and Research Committee of the State University of Feira de Santana, under Opinion n. 1,440,239, CAAE 49493315.3.10001.0053. After authorization from the Committee, participants were contacted, informed of the anonymity of the research and its purpose, and signed the Terms of Free and Informed Consent form.

The rigor in the study development was ensured by verification of the 32 items contained in the Consolidated Criteria for Qualitative Reporting (COREQ), related to the research team, the research project, and data analysis[14].

Type of study and location

This was a qualitative, exploratory descriptive study, conducted at the Municipal Center for Support of People with Sickle Cell Disease (CMAPDF), located in a municipality in the interior of Bahia, and the Bahia Association of People with Sickle Cell Disease (ABADFAL), located in the state capital of Bahia.

Methodological procedures and data source

Participants were selected by convenience, and 29 participants met the following inclusion criteria: a confirmed SCD diagnosis, 18 years of age or older, registered at the CMAPDF or ABADFAL. People with a report of pain at the time of the interview invitation were excluded, because pain implies suffering to other individuals, and negatively influences or intensifies the evocation of unpleasant memories.

Collection, organization and analysis of data

The data were collected in semi-structured interviews, guided by a script containing questions focused on the S/R theme as being helpful in confronting SCD. The interviews were conducted in person, in a private environment, with only the interviewee and the interviewer present. The interviews lasted between 15 and 40 minutes, were recorded in MP3 format, and then transcribed. The data were submitted to content analysis, from which emerged categories that were validated by six different researchers: three doctoral students and three master students.

RESULTS

Among the 29 participants, there were 12 women and 17 men, aged between 19 and 53 years; 20 individuals had SS hemoglobinopathy, seven had type SC, and two participants were unaware of their hemoglobinopathy. The level of education of eight participants was incomplete elementary education, 14 had incomplete high school education, and only six had completed their high school degree, and one had higher education. All participants had beliefs based on Christianity, eight of whom were Catholic, and nine were aligned with the neo-Pentecostal movement.

The categories, and their respective subcategories, that emerged from the statements are summarized in the Chart 1.

Chart 1 - Synthesis of the categories and subcategories evidenced in the statements, Salvador, Brazil, 2017

Experiences of spirituality/religiosity of individuals with sickle cell disease in coping with chronic illness		
Motivation for religious practices - Search for healing by means of a miracle - Fear of death	Spiritual and religious rites - Reading of religious texts - Individual and group prayer - Worship attendance	Effects on health - Comfort through coping by comparing two evils - Anxiety relief - Pain relief - Social support - Lifestyle change - Impaired spirituality

Motivation for religious practices

Search for healing by means of a miracle

The close relationship between the search for healing and the profession of faith can be understood in the interviewees' statements, in which expressions of belief in faith healing are common, according to the following fragments:

> [...]*The word says, he who believes will be healed, then, each one has a manner of believing and a manner of living what Jesus is in their life, my faith is not the same as everyone's faith, the faith of every one is different, the woman with blood flow had faith, but she had to lose to have more faith and be healed.* (E 03)

> [...]*I believe that Jesus is powerful; He is the God who heals as well. As the sickle cell is a disease that has no cure, God can heal it, I believe it.* (E 05)

The believers' belief in their recovery by means of a miracle is based primarily on biblical stories and participation in religious groups, where affirmation of faith healing is common in the statements of their religious leaders.

Fear of death

Fear of death is a motive that leads the individual to rely on S/R. By believing in a divinity who holds the conditions of the existence of life and death, this individual, in difficult times of illness, bargains with God to continue living; or through his religious beliefs, he begins to understand death in a more peaceful way, so this ceases to be a source of apprehension in his life.

> [...]*When I was younger, I was very scared of dying, today I have been able to think "God's will be done", I will do it by agreement, to be a normal person* [...] *that's what I learned to think, to be a normal person.* (E 10)

> [...]*because the Bible says that to die in Christ is to profit, coming out of that space, as the word says in John 15, verse 20, that "I am in this world, but I am not of this world" and He says that we have an eternal life, the flesh may perish, but we must believe in the eternal life that is Jesus.* (E 03)

When a person lives with chronic illness, which can cause several negative repercussions in his/her life, and that promotes a feeling of imminent death, it is understandable that beliefs are constantly centered on the search for answers that can attenuate the fear of death.

Rites, spiritual, and religious practices of people with Sickle Cell Disease

Reading of religious texts

Spirituality, although inherent in the human being, is usually related to religious practices; among them we can find the reading of the Bible, very commonly mentioned by the interviewees, and the reading of verses and religious texts that strengthen faith and bring comfort in difficult moments, as can be seen in the following statements:

> [...] *in a day of questioning I said "God, why so many bad times and why so many difficult moments?" Then I thought "God is not with me", then, an insight came to my mind take that message that your friend gave to you", then, I read this message: "in the most difficult moments of your life in my arms I carried you." In the message, He tells us to look back and see that only one set of footprints can be seen in the sand.* (E 10)

In difficult situations, the reading of biblical verses and religious texts enables the patients to reflect on the moment they living, and to find a relief for suffering in these words. They perceive, in this practice, a positive answer by which to confront the bad aspects of the disease.

Individual and group prayer

Expressions of faith through prayer are common in the statement of these individuals; and through these they seek contact with God, believing that their requests will be fulfilled. The answers to their petitions become the thermometer by which to measure the faith of these individuals, so it is the amount of faith that will bring results in the lives of those who cry out.

> [...]*Actually, I pray, my faith is in God and to get some energy from God, only praying. My problems, I get down on my knees, I surrender to God, I speak of my problems, my needs.* (E 04)

Prayer practices also prove to be beneficial, both for coping with illness and for other personal issues: through the statements is possible to perceive that these people find the strength to overcome their problems through supplication and prayer.

In addition to individual prayer, people who seek to manifest their faith through religious practices usually meet in groups, with the purpose of interceding for each other, and then, they believe that the possibility of responses to their petitions is greater, as can be observed in the statements:

> [...]*I think that every difficult moment of pain, both with me and with my brother, we ask God, we do the novena, novena to ask, novena to thank*. (E 10)

> [...] *we make a circle, a big clamor, in the individual prayer we kneel down and ask God, and in the prayer circle, begging, in this case everybody is begging; if someone needs anything, we introduce the cause of that person.* (E 11)

The meetings take place with individuals who have affinities and who share the same beliefs; in this practice, the participants employ their faith by means of supplications and intersections in groups, believing that this communion between them is appreciated by God.

Worship attendance

Participation in religious ceremonies is a common habit among those who practice faith by means of a religion; it is the meeting of several members of a religious doctrine, in which the individuals present can make their supplications and venerate their divinity; this practice is frequent among people with SCD, and some of them claim to be present in the church every day of the week.

> [...] *Monday has prayer, Tuesday has a study of the Word, Wednesday has a rehearsal and I am part of the group, Thursday has worship, Friday has rehearsal, Saturday has worship, and Sunday has worship, so normally I am in church all week.* (E 11)

The attendance of religious services may be due to the need to strengthen the faith, or because of the comfort that these rituals are capable of providing, as the most common reports among those interviewed was finding peace and tranquility when they are with other believers in religious temples.

Effects on health

Coping by comparing two evils

The religious practices adopted by the interviewees enable them to reflect on the situation of the individuals around them who, like them, have some disease or limitation, which confers on them a context as difficult as, or worse than, that which is being faced by the persons with SCD; in this way, this thought promotes comfort for the consequences of their disease. The following statements demonstrate this feeling:

> [...]*we think about our situation and that of others, because some people are worse than us, even if we suffer, some are worse* [...] *this is why we have to be patient and have faith in God.* (E 01)

> [...]*we can not only think about ourselves, we have to think that it's not just me, several people who are in the ICU now are needing God too, so I've learned to think like that*. (E 10)

The overcoming of adversities imposed by disease can also be achieved by the comfort provided by religious lessons; when thinking about difficult situations faced by other people, the individual with SCD finds resilience to face his/her own problems.

Anxiety Relief

Believing in the existence of a God who is able to control what happens in his/her life, the individual experiences a sense of relief from apprehensions, so that he/she shifts the focus from limitations of the disease and moves to responsibility for the future. Belief in the existence of this Being, who reigns over the events around him/her, and who desires the best for this individual, enables him/her to feel less anxious about the future. This thought can be seen in the following statements:

> [...]*I believe that things will follow naturally and based on that, I act.* (E 04)

> [...]*We feel the presence of God, and we are there, asking for something that we know He will solve*. (E 11)

While a person, who does not have any chronic illness, most of the time, plans and realizes his/her plans, the chronically ill patient is restricted, due to the inconsistency of his/her state of health; this situation leads to many frustrations and anxiety. However, a belief that one's life is being governed by a higher power usually mitigates these feelings, as seen in the statements.

Pain Relief

The person with chronic pain needs to use resources to adapt to these painful sensations, and the possible changes in his/her life. One of these resources, which can be seen in these statements, is S/R.

> [...]*When we were in the same crisis, we ask for Jesus, and many times we are relieved, it has passed.* (E 11)

> *Once I had to get my son in school, but then, I had a very strong pain, and I prayed, I rebuked, and I became good at the same time.* (E 05)

> [...]*it is a comfort when the person is in pain. I asked God, a lot, to relieve, and sometimes I took a medicine and I went to bed, then I woke up and thanked God ... Without faith, without religion, we are nothing, everything is worse; We have to believe in something.* (E 01)

One of the benefits of faith and religion found in the statement of individuals with SCD was their process of seeking pain relief, as their practices of faith developed, individually or with the help of members of their religious communities, these are pain coping strategies that promote relief and comfort.

Social support

The welcoming, material and psychosocial support of the members of the religious organizations of which people with SCD are a part, which are demonstrated by prayers, financial aid, and words of comfort and encouragement at times of worsening illness, provide support to these individuals. The effects of these actions can not necessarily remove the symptoms of the disease, but can change the meaning attributed to it in such a way that the sick person feels relief from the ills of the disease, as can be seen in the following statements:

> [...]*I felt good, it was good* [...]*it was good that he gave a word, a thing, a comfort* [...] *He speaks to the person, for him to be patient.* (E 01)

> [...]*Sometimes you feel discouraged, you feel sadness, but by the words, prayers and encouragement we feel refreshed, you know? Refreshed inside; only those who go through it, feel it.* (E 04)

Being together with other people, sharing their emotions, yearnings, or even professing their faith with other individuals is shown to be something positive for improving the distressing feelings of the one who suffers from chronic illness. During these congregations, the interviewees report receiving support from the members in an unrestricted way, capable of covering other aspects that surpass the spiritual sphere.

Lifestyle change

Spirituality is capable of reaching a highly diversified range, because in addition to the questions involving itself, changes in the lifestyle of these people can occur. When manifesting their spirituality through a religion, this subject submits to the imposed moral norms for individual and social conduct; in this way, it is prone to change their habits of life, as we see in the next statement:

> [...]*Because in these visits, God began to talk to me, began to use people to talk to me, then I realized that God was calling me to a commitment, then I was baptized ... and I was also in a half-wrong world* [drug use]*, and God helped me because, church is good because it is the meeting with the body of Christ, but without God it is nothing, understand?* (E 11)

> [...]*Before I used to drink, I used to go to parties, but every time I was having fun and enjoying it, finding it wonderful, I just suffered more and more, and then I said I was not going to do that anymore. I saw that God was good to me and I've changed. And I saw that the reason for living was God and that's when I began attending worship and seeing the changes. Even my health improved. I was having a crisis twice a week* [...] *I was going out, and when I got home, I had crisis because I drank, and when I stopped everything, a radical change happened in my life.* (E 12)

Changes in the habits of life, by means of the religious conceptions imposed by a religious doctrine of which the individual becomes part, are seen by the people as something positive in their lives. Dogmas stimulate healthier lifestyles, as identified in statements about abstention from smoking and alcohol.

Impaired spirituality

Despite the positive aspects already mentioned, S/R can also be manifested in a detrimental way, as the negative repercussions of the disease promote a feeling of "orphanhood" in the person towards his God. The individual inquiries through religious beliefs, the reason for the complications and sufferings triggered by the disease are noted. Although some statements demonstrate the risk of spiritual suffering, others denounce the experience of this feeling, as we can perceive in the statements:

> [...]*when I was younger I thought like this "no, faith is not useful, because nothing goes forward, nothing evolves", because a person with 20 years of age, everything must be evolved, except that in my life everything was always overdue, understand? Then I questioned God very much.* (E 10)

Often, spiritual suffering is demonstrated by contradictory statements, because, at the same time that the individual refers to not believing in a God, he affirms that God abandons him. So, we perceive that he is in spiritual agony, as seen in the following statements:

> [...]*it is difficult to have faith or to believe in God with this problem ... The guy there, is in pain, he does not call for God or anything ... I feel kind of abandoned in this disease, I don't know* [...]. (E 02)

> [...] *I used to think that this was a punishment*. (E 01)

In addition to the feeling of abandonment, it is possible to perceive references to divine punishment, something very common and widespread in the Middle Ages, but which can still be found today in the statements of chronically ill people. This perception, of being punished by God, must also be considered as a source of spiritual suffering, because it leads the individual to enter into conflicts with himself and with God.

DISCUSSION

Believing in healing by means of a miracle has proved to be a common occurrence among people with SCD, and a motivator for religious practice. Additionally, when chronic kidney patients were asked about the importance of religion in the treatment of their

disease, 90% of the patients responded: "hoping that I will improve." This clearly demonstrates the relevance of spirituality and religion in the treatment of chronic diseases, insofar as they are accumulating hope, making each patient's life more dignified and comfortable[13].

People with SCD live with eminent death due to the consequences of the disease; for this reason, the feelings related to the stages of mourning may be constant in their lives. However, S/R are able to promote the feeling of acceptance in these individuals, which gives them more tranquility and dignity to deal with the fear of death. Studies show that when facing feelings of the fear of death, faith is a consolation and a hope[15].

Thus, the individual adopts practices that are comforting in times of distress: reading Bible verses and religious texts, for example, has a strong influence on the behavior and attitudes of these people. Among the rituals are also found prayers and novenas that are widely used among those who seek to face the illness through the lens of faith. These findings reinforce the research findings, which state that praying is a common and comforting practice in a time of difficulty, and that the exercise of spiritual activities can influence individuals psychodynamically, through positive emotions. Such emotions may be important for mental health, in terms of possible psychoneuroimmunological and psychophysiological mechanisms[16-17].

Another behavior common to the interviewees is attendance at religious worship and services of their churches, with only one who denied going to the church very often. This finding was also supported in a cross-sectional study in which almost the entire sample (99.1%) reported having a religious belief. When estimating the public religious practices in the last three months, 51.8% of the patients reported a high attendance rate (one to seven times a week), while 33.6% had a low frequency (one to six times a month). As for private practices, the majority of participants (59.1%) said they practiced religion privately every day, sometimes more than once a day[18].

Among the repercussions of the spiritual and religious practices for individual health, the coping by comparing two evils, as a form of resilience, was perceived in the statements of the subjects. To evaluate the effectiveness of coping, it is necessary to verify the possibility not only of solving the problem, but also of controlling it. This approach mainly refers to situations that are without solution and permanently stressful, as in the case of chronic diseases, in which the absence of projections for cure requires many more strategies to control emotions and situations than with confrontational actions[19-20].

Anxiety relief, through faith, is explained in the literature as a result of the improvement of the psychological state due to surrender of control of one's life to a supreme being. This creates a better strategy to deal with and to reduce stress, with the consequent optimization of psychoneuroimmunological, psychoneuroendocrine, and psychophysiological pathways[21].

The search, clamor, and prayer noted in the statements of the interviewees are religious elements that enable that individual to connect with God, and it is through these practices that one receives relief for anxiety. These tools are a form of living communication between the devotee and a God, imagined as personal and experienced as present. This communication reflects the form of social human relationships[22-23].

Faith and religious practice provide a reduction in total pain, which includes not only the physical aspects of pain, but also its existential expression on the psycho-emotional and social dimensions of the disease. There are innumerable benefits to religious involvement in coping with the countless manifestations of chronic illness. Much evidence indicates that spiritual practices help in reducing hormonal secretions that decrease immune cell counts, and that are involved in stress. On the other hand, it is known that religiosity helps in relieving pain, since it increases the amount of neurotransmitters involved in this control[24-25].

The meaning of support provided by social groups, such as those created in churches, can be understood as emotional, material, and informational resources that subjects receive by means of systematic social relationships, including from the most intimate relationships with friends and close relatives to even higher social relationships, such as religion. In this way, the support of other members of the institutions, of which that person is a part, proves to be important in confronting the illness, because, given that it is a spiritual aid institution, the welcoming, prayers, and attention given to the person with SCD are seen as giving comfort[26].

Changes in lifestyle, by means of religious practices, are also noticed in people with cancer. Faith helps to restructure a healthier lifestyle. Respondents cited that faith and religious practices made them change their way of living life, even after illness. In this way, they changed their habits to improve their quality of life. Religion also positively influences the state of health, as it teaches and instructs on protective behaviors, and of behaviors supporting health. Therefore, the individual quits smoking, stops using alcohol, begins to demonstrate positive behaviors, such as prayer, or meditation, which offer emotional comfort and stress reduction[27].

NANDA International (NANDA-I) recognized *spiritual distress* (code 00066), as a pertinent nursing diagnosis. Nevertheless, this diagnosis is rarely identified in practice, because of its complexity, the nurse's difficulty in identifying its evidence, or due to the gaps related to this aspect of knowledge and, very often, lack of interest in the phenomenon of spirituality[28].

The disease generates existential conflicts that can cause spiritual distress, which, in turn, aggravates physical and emotional symptoms and the capacity to face the disease[29]. This statement was confirmed in this research, as the reports of some interviewees showed a disturbance as a consequence of the perception that the disease is a punishment, or the thought that they were abandoned by their God.

Limitations of the study

The present study had, as a difficulty, the time available for interviews with participants, because they were performed in a private room while the interviewees awaited medical consultation. Thus, at certain times, an interruption in the interview was necessary, making it more difficult to conclude the interview.

Contributions to nursing, health or public policy area

The results of this research bring to light the need to qualify health professionals to address the spiritual issues of the people for whom they are caring, with the concern of diagnosing possible suffering and anguish, and providing help and comfort, or even strengthening spiritual bonds.

Thus, health professionals could recognize that patients' spiritual needs can be impaired, and through their appreciation and encouragement, could support the strengthening of the spiritual bond of this individual who already has his/her own S/R beliefs.

Further studies on the subject are recommended, investigating the knowledge and the manner of dealing with S/R by health professionals, to understand the perceptions and meanings attributed, as well as to explore the preparation to address these issues.

FINAL CONSIDERATIONS

Individuals with SCD adopt rites and spiritual and religious practices to overcome difficulties, and to adapt to the deleterious effects of the disease, either individually or by integrating with religious groups. Due to the search for healing, and a constant fear of death, the participants seek religious readings; participate in the daily life of churches, worships and novenas. In addition, the S/R of those who have SCD leads to relief of symptoms, increased hope, comfort, and lifestyle change. Meeting the need for S/R may also be affected by pain, and constant hospitalizations for treatment, which impose limitations on participation in religious practices.

In view of the difficulties faced by those who have this disease, and the complexity of having a positive impact on their quality of life, a more sensitive view of their needs is important. In order to accomplish welcoming, it is necessary to consider the need for spiritual and religious support for the individual, among other aspects. Without this kind of care, it is not possible to contemplate all dimensions of the human being, in such a way that care provided becomes very limited. Neglecting the spirituality of a patient is a failure of comprehensive care for that individual.

The results of this study emphasize the need to qualify health professionals to address the spiritual issues of the individual for whom they are providing care, with the concern of diagnosing possible suffering, anguish, and thus, being able to provide help and comfort, or even to strengthen their spiritual bonds.

The use of religiosity in coping with chronic illness should not be understood as a tool, but professionals must recognize that spiritual needs can be impaired in these individuals, who already have their own spiritual/religious beliefs, and by means of their appreciation and encouragement they can support them in strengthening their spiritual bonds.

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