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Spiritual needs of Brazilian children and adolescents with chronic illnesses: A thematic analysis

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ABSTRACT

Purpose: To identify the spiritual needs of children and adolescents with chronic illnesses and how these needs are met by health professionals during hospitalization.

Design and methods: A qualitative descriptive study was developed with 35 children and adolescents, between 7 and 18 years old, diagnosed with cancer, cystic fibrosis, and type 1 diabetes. Interviews with photo-elicitation were conducted during the hospitalization at a Brazilian public pediatric hospital. Findings were treated using thematic analysis, and the Consolidated Criteria for Reporting Qualitative Research (COREQ) was followed for quality reporting. This research was approved by a research committee.

Results: Two themes emerged. The first, entitled 'Spiritual needs', encompasses five types of needs: (1) need to integrate meaning and purpose in life; (2) need to sustain hope; (3) need for expression of faith and to follow religious practices; (4) need for comfort at the end of life; and (5) need to connect with family and friends. The second theme was the 'Definition of spiritual care'.

Conclusions: Children and adolescents with chronic illnesses have spiritual needs while in hospital. Meeting these needs is essential for finding meaning, purpose and hope in the experience of living with chronic illnesses and at the end of life, based on their faith, beliefs and interpersonal relationships. But, these needs have not been fully addressed during hospitalization.

Practice implications: These results emphasize the need to implement spiritual care when caring for hospitalized pediatric patients, which includes addressing spiritual needs.

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Introduction

The prevalence of children and adolescents living with chronic diseases has increased in the past 50 years (Passone et al., 2020; Perrin et al., 2014). Currently, it is possible to perform detection, early

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diagnosis and treatment of many diseases in children and adolescents, which previously were fatal. Thus, the increase in survival has critical implications resulting from chronicity (Passone et al., 2020). Diseases such as cancer, type 1 diabetes mellitus (DM1) and cystic fibrosis, are common in childhood and demand daily care for long term periods (Mokkink et al., 2008).

The condition of living with chronicity can cause physical and financial impacts on families and children, and may develop into emotional and behavioral problems (Compas et al., 2012). Despite this, families who live with chronicity seek new perspectives and possibilities within the limitations of the disease (de Araújo et al., 2011), through reflection on their own experience and perception of well-being (Spurr et al., 2013). The child may use spirituality to find answers to the meaning

and purpose in life, to improve coping processes, and as a resource to strengthen hope (Leite, García-Vivar, Neris, Alvarenga, & Nascimento, 2019); Compas et al., 2012; Lima et al., 2013).

Spirituality is a natural dimension, independent from but also related to religion, and cannot be separated from the child's individuality. The child's concept of spirituality is focused on relational awareness, which means the way in which children relate to themselves, to people, to the world and to God (Hay & Nye, 2006). Relational awareness favors to reflect on the lived spiritual experiences, the development of identity, and the understanding of meaning and purpose in life, which are critical for the perception of spiritual and emotional well-being (Hay & Nye, 2006). The concept of spirituality is often described in literature as involving three main components: connectedness, transcendence and meaning of life (Weathers et al., 2016). In addition, the way of expressing spirituality seems to vary depending on the age, and the environment the child finds him/herself in to communicate about spirituality and specific experiences (Damsma Bakker et al., 2018).

Healthcare professionals, as members of a healthcare team, must be qualified to identify and provide spiritual care to hospitalized children and their families (Cooper et al., 2020; Damsma Bakker et al., 2018). By being aware of the religious and spiritual practices, life experiences and beliefs of their patients, nurses can help in coping with the disease (Alvarenga, Carvalho, Caldeira, Vieira, & Nascimento, 2017) and, thus, provide comprehensive care (Blinded for peer review). A deeper understanding of spirituality and spiritual needs as experienced by patients is critical in implementing spiritual care. A scarcity of studies exploring the spiritual needs of the pediatric population is often described in the literature (Damsma Bakker et al., 2018), and there is a need for the following: (a) studies with participants under the age of 12; (b) studies that compare spirituality according to different diagnoses; and (c) research involving non-religious children. More studies are needed to improve the evidence about spirituality of children and adolescents with chronic illness. In this way, this study aimed to identify the spiritual needs of children and adolescents with chronic illnesses and how these needs are met by healthcare professionals during hospitalization.

Methods

Study design

This is a descriptive study with a qualitative approach (Glaw et al., 2017). Photo-elicitation interviewing was used to answer these research questions: "What are the spiritual needs of hospitalized children and adolescents with chronic diseases?" and "How have healthcare professionals, especially nurses, attended to the spiritual needs of these patients?". The consolidated criteria for reporting qualitative research (COREQ) checklist was used (Tong et al., 2007).

Participants and setting

The study included 35 children and adolescents aged between seven and 18 years old, all admitted to hospital for clinical treatment (Table 1). To be eligible participants needed to be diagnosed with cancer, cystic fibrosis or type 1 diabetes mellitus for at least three months. The inclusion criteria concerning defined age was determined by considering the linguistic development of participants, and the criteria in regard to diagnosis time was determined by considering that this was the minimum length of time needed to experience the disease and reflect about aspects of spirituality at this phase of life. The exclusion criteria were as follows: children and adolescents unaware of their diagnosis, had a level of development below seven years or not compatible with age; had language problems that impaired speech or visual deficiencies that would impair the viewing of the photographs. Before inviting them, we talked to the family to find out if the children and adolescents knew of their diagnoses and if they would be available to talk about spirituality. In addition, children and adolescents were subsequently consulted about their desire to

Table 1
Characterization of participants.

Characteristic	Frequency	Percent (%)
Age range (in years)		
7–12	15	42.8
13–18	20	57.2
Gender		
Female	17	48.6
Male	18	51.4
Chronic disease		
Cystic fibrosis	5	14.3
Cancer	20	57.1
Type 1 diabetes mellitus	10	28.6
Diagnosis time (months)		
3–6	12	34.3
7–11	5	14.3
≥12	18	51.4
Level of education		
Elementary school	8	22.9
Middle school	19	54.3
High school	8	22.8
Religious affiliation		
Evangelical	14	40
Catholic	13	37.1
Umbanda (Afro-Brazilian religion)	1	2.9
Spiritism	1	2.9
No religion, but spiritual (believes in something)	1	2.9
No religion and not spiritual (does not believe in anything)	0	0
Atheist (does not believe in God)	5	14.2
Religious practice		
Yes	28	80
No	1	2.8
Does not have any religion	6	17.2

participate in the study. Seven participants declined to participate for reasons concerning the clinical condition, the lack of interest in the topic or shyness with the use of the recorder.

The study was conducted in the Pediatric Inpatient Unit of a public hospital, located in southeastern Brazil. The sample resulted from intentional sampling and the interruption of data collection occurred with code and meaning saturation (Hennink et al., 2017).

Data collection

Data collection was performed by a nursing graduate student trained and supervised by a doctor and a doctoral student in nursing. None of the researchers had a professional relationship with the data collection scenario or had contact with the participants before the research.

Clinical and social variables (Table 1) were collected from the questionnaire designed by the authors. Individual audio-recorded interviews were carried out with the support of six photographs (Table 2). This technique is known as photo-elicitation interviewing and the set of photographs and guiding questions used were adapted from a model for addressing spirituality developed from a literature review, then evaluated by a committee of experts and tested with children and adolescents with cancer (Alvarenga et al., 2020). We adapted the conversation model of 20 photographs to six photographs which responded to the aims of the study. We also conducted a pilot test with two adolescents with cystic fibrosis and type 1 diabetes mellitus to determine whether the interview guide truly elicited the participants' spiritual needs. The interview guide was centered on the following areas: the experience of the disease and the role of religion/spirituality in the life journey; life meanings; religious/spiritual beliefs; and resources used to cope with the disease (religious/spiritual beliefs, family, friends and health professionals). The photographs were used as a support for the interview, since using visual resources, such as photo-elicitation, is a way to maintain a more interactive and relational conversation for a deeper and more complex understanding of the phenomenon being studied (Alves et al., 2018).

Table 2
Interview guide.

Description of the photo	Questions
1 A girl alone, looking at a long road that is behind her	Tell me what it was like when you discovered the disease. What changed in your life after you discovered the disease? Do you suffer from having this disease?
2 A girl looking at the stars through her bedroom window	Do you wonder why you have the disease? What questions do you ask yourself today about your illness? What helped you find those answers?
3 A child in bed with her mother who has an expression of concern, talking to the doctor	What things can healthcare professionals do if a patient has spiritual concerns? Can you share an example of an interaction when you felt your spirituality was considered? Is there anything you believe you would like health professionals to know?
4 A teenager walking alone on the train tracks, towards a bend with bright light	Do you think it is important to believe in something to live better with the disease? What do you usually do/believe that will help you during your treatment? Do you have hope? If yes, what are your sources of hope?
5 An adult's hand holding the hand of a child	What is your family's role in relation to your illness? Who in the family do you think suffers most from your illness? Does your family help you keep your hope?
6 Group of cheerful teenagers holding hands at sunset on the beach	How did your friends help you live with this disease? How do your friends prevent you from living with this disease? Do they help to keep up your hope? How?

Source: Adapted from (Blinded for peer review).

During data collection participants were curious about the photographs and started talking about spirituality spontaneously. If any signs of tiredness or desire to interrupt the conversation were observed, the participant was asked about the possibility of continuing the interview at another time and the ending of that interview was suggested.

Thus, data collection was conducted individually and could be performed more than once, as deemed necessary by the child/adolescent. Two participants preferred to conduct more than one individual interview. Each individual interview lasted approximately between 18 and 70 min.

Considering that participants are pediatric patients, caregivers could be present during the interview, and the child/adolescent was given this option (Spratling et al., 2012). The presence of caregivers was not perceived as an influence on the interview. Upon completion, field notes were made.

Data analysis

The data analysis was carried out in six stages, according to the inductive thematic analysis (Braun & Clarke, 2006): (1) two researchers (WAA; JRM) became familiar with the data through the exhaustive reading of the transcribed interviews, the data of clinical characteristics and the field notes; (2) the researchers (WAA; JRM) identified initial codes inductively, grouping the data by age (children and adolescents) and then by chronic disease, in line with the research question; (3) from the initial codes, themes that represented the studied

phenomenon were constructed; (4) two other researchers (ACABL; LCN) jointly reviewed and validated the constructed themes in order to achieve the desired level of abstraction and the reliability of the results; subsequently, (5) the themes were named to represent the data analysis; and, finally, (6) the final synthesis of the results was constructed and we also used diagramming as a way to make sense of the connections between themes, which were reviewed and validated by all authors. All steps were conducted through data analysis and followed the trustworthiness criteria for conducting thematic analysis (Nowell et al., 2017).

Ethical considerations

Ethical approval was granted by the ethics committees of the university institution supporting the research and the hospital where the study was developed. Written informed consent was obtained from parents or caregivers. Afterwards, children and adolescents were consulted about their desire to participate and their signature was obtained on the assent form. Researchers only included children and adolescents who gave their own assent and the consent of their parents or caregivers.

Results

Two themes were constructed: the first, 'Spiritual needs', which encompasses five types of needs: (1) the need to integrate meaning and purpose in life; (2) the need to sustain hope; (3) the need for expression of faith and to follow religious practices; (4) the need for comfort at the end of life; and (5) the need to connect with family and friends. The second theme was 'Definition of spiritual care' (Fig. 1).

Spiritual needs

Need to integrate meaning and purpose in life

Children and adolescents sought to integrate meaning and purpose in life to understand the suffering experienced and the changes resulting from chronic illness. Children and adolescents sought to make sense of the disease and suffering by asking existential questions, such as: "Why me?". Participants' purpose in life and existential questions were intensified by the fact that they did not understand or accept the physiology, treatment and prognosis of the disease

"I ask myself questions [shows sadness], why did this disease come to me? [silence]" (Adolescent 2, 14 years old, Cancer, Male).

Children and adolescents integrated the meaning of the disease and purpose in life with their religious beliefs, for example, thoughts that they are "paying" in this life for mistakes in a past life or that the disease was part of a plan of a benevolent God.

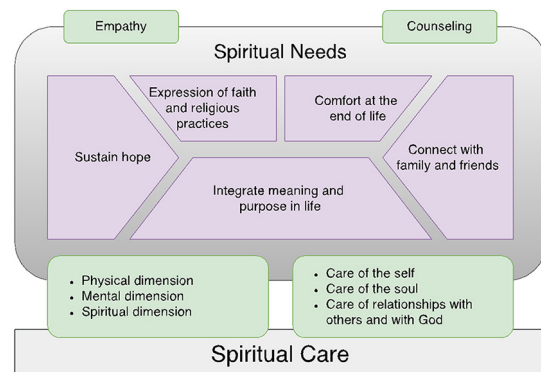


Fig. 1. Spiritual needs and spiritual care of hospitalized children and adolescents with chronic diseases.

"I was convinced that it was a passing thing. God chose me and it was just an experience that I needed to go through, for me to mature, to teach myself. I learned that God gives and takes away" (Adolescent 6, 16 years old, Cancer, Female).

Non-religious beliefs were also cited by children and adolescents, when they believed that the disease was related to genetic and behavioral factors and promoted personal growth.

"This disease happened to me because of my diet. I had cancer to make me start eating better. I didn't eat fruit and vegetables" (Child 13, 12 years old, Cancer, Female).

Participants reported that the interaction with the family and health professionals also contributed to the integration of meaning based on information about the disease, which resulted in the understanding and acceptance of chronicity.

"My mother was the one who helped me find answers by asking the doctors. Time also helped. [...] My doubts were: how long will it stay like this, how would my recovery be, what would be the type of treatment, various things. Over time, the professionals responded and I became more relaxed, because I learned about things" (Adolescent 20, 15 years old, Cancer, Male).

Need to sustain hope

Children and adolescents needed to have hope, especially about their future. Hope was related to healing, returning to regular daily life, achieving life projects and maintaining relationships with family and friends for life, regardless of health conditions.

"When I look ahead [...] I see another life, only better. After treatment I will be free [laughs]. It will still take a couple of years, but I'm not in a hurry" (Adolescent 6, 16 years old, Cancer, Female).

However, according to children and adolescents the unpredictability about how the disease will impact on the future, negative thoughts, and interpersonal relationships with health professionals and with family members were all capable of causing a decrease in hope and optimism.

"I imagine that there could be a lot of good things in my life. I really want to be a veterinarian. But the road we still have to follow is very long [cries]. I can't imagine what could happen to me, only if I stay alive [crying]. Because it's difficult every time you come here [hospital] and they [doctors] tell me that I almost died again. This is the 6th time they have told me this" (Child 5, 10 years old, Diabetes Mellitus, Female).

According to the participants, controlling negative thoughts, self-care, faith, meaningful interpersonal relationships, psychological support and exchanging experiences with peers were all elements that are able to promote hope.

"Meeting other patients helps me to keep up hope, because it's not just me who goes through these problems, others also do [Crying]. [...] Professionals help me psychologically to keep up hope. They help with words of support and that comforts me" (Adolescent 17, 14 years old, Diabetes Mellitus, Female).

Need for expression of faith and to follow religious practices

Children and adolescents needed to express faith and follow religious practices, as most of them reported holding a belief in the existence of God ($n = 30$; 85.7%) and in the miracle of healing ($n = 6$; 17.1%). Their faith was based on the belief in a benevolent God who acted divinely in adverse or near-death situations.

"I think that to help me with the treatment I need to have a lot of faith in God and He will help me. I think He has given me many chances to live. I like God a lot [crying]" (Child 5, 10 years old, Diabetes Mellitus, Female).

"I'll have faith forever, until God achieves the miracle of healing me" (Adolescent 17, 14 years old, Diabetes Mellitus, Female).

They usually practiced religious rituals at home or in the hospital (reading the bible and praying). These practices were perceived as positive in the psychological domain, based on the perception of being calmer, stronger, more comfortable and in a more intimate relationship

with God; and also in the physiological domain, such as a decrease in their glycemic level.

"Prayer helps me, because prayer is nothing more than talking to God, it brings me comfort. It's not routine, like having to talk to a doctor, so it brings intimacy with God, which is important to me" (Adolescent 6, 16 years old, Cancer, Female).

Children and adolescents also reported that they felt supported by the religious community and relieved when religious members say words of comfort:

"In the church, they say it is up to me to do it right, it is up to me to believe that this diabetes will be controlled. That's why I'm being hospitalized, to control it a little bit" (Child 4, 10 years old, Diabetes Mellitus, Female).

Participants believed that health professionals could meet the need for the expression of faith and religious practices, by allowing visits of religious members during hospitalization, granting hospital discharge so that the patients can go to church and practice intercessory prayer or praying together with them. Only one teenager with diabetes mellitus reported believing that professionals could not help with this need.

"What professionals could do to help me have this relationship with God is pray. If you want to pray with me, alone, or with anyone, it's so that God can heal or help. [...] The professionals could allow the missionary to come here, it would help me to have a relationship with God" (Child 11, 10 years old, Diabetes Mellitus, Male).

There was duality about the desire to share religious beliefs with health professionals. Some considered it important to share their beliefs in order to build a trusting relationship. Others considered it a private subject, and felt ashamed in doing so or, on the other hand, ashamed in maintaining a distance from the professional, when both did not share the same religious background.

"I think it would be important if the professionals knew about my beliefs, because that way they can get to know me better, it can prevent them from doing something that I don't like" (Adolescent 6, 16 years old, Cancer, Female).

"There is nothing about my religion that I would like them [professionals] to know. Maybe it would have consequences, because they are not Catholics like me. I am afraid it would create a distancing" (Adolescent 14, 14 years old, Diabetes Mellitus, Female).

Need for comfort at the end of life

Children and adolescents expressed needs related to the end of life, such as the need to ensure their future after death and the well-being of their family, to be with significant people, to forgive and to feel satisfaction with life.

"If I had a few days to live, I would prefer to go to my home, be in the comfort of my family, the people I love, to attend church. Because there I know that there are people who really love me, who know me, who have a real affection for me and I would prefer to die with people like that" (Adolescent 6, 16 years old, Cancer, Female).

Although they were afraid and reluctant to talk about death, they reported beliefs related to life after death, such as the existence of a divine plan, hell, heaven and the need to secure the destiny of souls.

"I was afraid of dying because I thought I was going to stay there on earth with a lot of scorpions biting me. Now that I know that if I die, my soul will go to heaven and only my flesh will stay" (Child 11, 10 years old, Diabetes Mellitus, Male).

They believed that health professionals could contribute to meet their needs at the end of life. This could happen through empathy, maintaining an ethical performance and taking care of physical and psychological needs, with their family members advising to keep positive thoughts and understanding of the lived experience.

"When someone dies, the professional must give support to the family by talking, trying to make them understand that there was no other way" (Adolescent 8, 14 years old, Diabetes Mellitus, Male).

Need to connect with family and friends

Children and adolescents reported the need to connect with family and friends, as a source of faith, peace and support to deal with the challenges of illness and the finitude of life. The family always provided support, showed love, and encouragement to keep persevering the treatment.

“My father takes care of me; he has changed to take care of us. He’s someone who’ll take your hand, pull you in and say”: come on, I’m going with you, I’m going to fight with you. “This is important in the life of someone who’s ill, it is important to know that there are people who care about you” (Adolescent 6, 16 years old, Cancer, Female).

Participants also mentioned the need for connection with a deceased family member, which was significant for children and adolescents. The loss of the family member resulted in a crisis of faith and a feeling of disconnection, longing and discouragement to continue with the care required by the disease. Children sought to re-establish the connection with the deceased individual when looking at the sky and feeling their presence. They found solace in the belief of a reunion after death, that their family member is in a good place and that God did what was best.

“I like to look at the sky, because of my grandmother. I liked her a lot. I like to think that she is always here by my side, helping me. I miss her so much and that’s why I don’t like talking about it so much; because I always cry a lot” (Child 5, 10 years old, Diabetes Mellitus, Female).

Friends were also important for children and teenagers. They offered moments of joy, support and encouraged therapeutic adherence. According to children and adolescents, the maintenance of this connection was in person or virtual, using social media.

“My friends help me and I’m not sad. Sometimes, I’m here and I talk to some of them on WhatsApp, [and I say] ‘What’s up, okay?’ So I don’t get bored with having nothing to do” (Adolescent 7, 14 years old, Cystic Fibrosis, Male).

They believed that health professionals could contribute to meet this need by allowing family and friends to visit them in the hospital and stimulating this connection between them.

“Sometimes we want nothing more than a hug, the comfort of someone we love. So it is important that they [health professionals] allow us to have the people we love close to us” (Adolescent 6, 16 years old, Cancer, Female).

Definition of spiritual care

Spiritual care was defined by children and adolescents as the care of the self, the soul, relationships with others, and with God. Empathy and counseling were central to this care according to children and adolescents. Health professionals were empathic when they have the ability to understand the patient’s feelings. During counseling, health professionals provided information to patients and helped them, gaining insights about their beliefs, values, and behaviors. Therefore, patients are able to be supported and spiritually comforted during hospitalization. Spiritual needs, physical care, disease-related needs, and the mental dimension, were integrated into spiritual care according to children and adolescents.

“Spiritual care is taking care of relationships, taking care of who you like, what you like” (Child 19, 11 years old, Cystic Fibrosis, Male).

“What doctors, nurses and professionals here at the hospital can do to take care of this part, the spiritual, is to advise. They can also bring good things, not material things, but thoughts, conversations. They took care of this spiritual part of me yesterday, when they brought me words of support. It helped me because I was in need” (Adolescent 17, 14 years old, Diabetes Mellitus, Female).

The quality of care, perceiving security and comfort provided during hospitalization were reported as important for children and adolescents so that they felt spiritually supported. Situations characterized by a lack of support, empathy and humanization in care were disassociated from spiritual support.

“I like having the professionals close to me, it gives me spiritual comfort” (Child 12, 12 years old, Diabetes Mellitus, Male).

“The professionals talked to me, asked me if the food was good, if I wanted anything. At that moment, I think my spirituality was considered, because I felt important, someone coming all the time to ask if you are okay” (Adolescent 18, 16 years old, Diabetes Mellitus, Male).

An adolescent diagnosed with diabetes mellitus shared that patients should start the conversation about spiritual issues, as the professionals would not be able to identify this need. However, a child diagnosed with cystic fibrosis stated the opposite, since patients could be shy and may not be able to go deeper into aspects related to spiritual issues. Thus, it should be the initiative of health professionals to start a conversation on matters related to spirituality, allowing for relief of emotional burden and strengthening of care.

“Who should start talking about this [spirituality] is the health professional, because I wouldn’t want to talk too much, but if they started this topic, I would tell the person everything” (Adolescent 20, 15 years old, Cancer, Male).

As much as spiritual care was necessary during hospitalization, children and adolescents with cystic fibrosis and cancer reported that their spiritual needs were not met due to the professionals’ lack of time to address the topic and the patient’s lack of interest in starting the conversation:

“I don’t think the professionals considered my spirituality. I didn’t notice. Nobody asked me and also, I think they don’t have time, they have a lot of people around here”. (Adolescent 20, 15 years old, Cancer, Male).

Discussion

This study concerns spiritual needs of children and adolescents with chronic illnesses and how these needs are met by healthcare professionals. Children and adolescents with chronic illnesses have different spiritual needs during hospitalization, such as the need to integrate meaning and purpose in life, to sustain hope, to express faith and follow religious practices, to find comfort at the end of life, and to connect with family and friends. What is more, the definition of spiritual care has been reported to involve caring for the self, the soul, and relationships with God and with others. The use of photographs as a technique combined with an interview seemed to strengthen data collection, as it was possible to go deeper into aspects of spiritual needs.

The suffering resulting from the diagnosis of a chronic disease and the subsequent recurrent hospitalizations has an impact on the spiritual dimension of children and adolescents, including the emergence of spiritual needs. Spiritual well-being, communication, quality of life or adjustment to the chronic condition can be harmed by life experiences and stressors resulting from illness (Alvarenga, Carvalho, Caldeira, Vieira, & Nascimento, 2017; Damsma Bakker et al., 2018). Feelings of disconnection from oneself, family or community can also be consequences of illness (Jackson, 2012).

The need to connect with others, including the sacred, the family, deceased relatives, friends and health professionals, integrated the spiritual needs of the children and adolescents in this study. These findings corroborate with Hay and Nye’s (2006) concept of relational awareness and highlight the need and importance of relationships for the child’s spirituality (Damsma Bakker et al., 2018). These connections, which also involve friends, are necessary for support, normal hospitalization and perception of purpose in life (Clayton-Jones et al., 2016).

The need for expression of faith and religious practices denotes the influence of religion in the lives of children and adolescents, who mostly have a religious affiliation. Faith was considered a fundamental and indispensable dimension of life, being interrelated with the self, others and God (Dyess, 2011). Other studies have also shown how the relationship with God helped pediatric patients to reframe the experience of illness and find hope, comfort, strength and direction in life (Clayton-Jones et al., 2016; Hodge & Horvath, 2011).

The relationship with God is reinforced in the present study by religious faith and the challenging and near-death situations resulting from chronic illness. The diagnosis of a disease causes the family and the patient to seek shelter in the religious community, as participation in religious services can promote comfort and the expression of faith (Zerbetto et al., 2017).

Participants highlighted the need to integrate meaning and purpose in life. Questioning the meaning of life and the illness involved existential issues related to the physiology and prognosis of the disease. The re-establishment of the meaning and purpose of life is related to the acceptance of the chronic condition and the beliefs that integrate with the purpose of life (Clayton-Jones et al., 2016). For this reason, children and adolescents seek to find the existence of a reason for this experience and that the future may still be promising (Leite, García-Vivar, Neris, Alvarenga, & Nascimento, 2019).

The fear and unpredictability of the future generated by the consequences of treating a chronic condition created in the participants of this study the need to sustain hope. The hope for normalcy, positive expectations regarding treatment, optimism, courage and confidence to live life and achieve dreams characterized this need. The fear of the future impacting on hope was also highlighted in a literature review on the hope of families of children with chronic illnesses (Leite, García-Vivar, Neris, Alvarenga, & Nascimento, 2019).

In this study, the connection with healthcare professionals was essential for spiritual care and was reported as a necessity. Spiritual needs when met allow for the expression of feelings, concerns, purpose and hope (Petersen, 2014). The strengthening of relationships and beliefs for better coping with the disease are other benefits of attending to spiritual needs (Lima et al., 2013; Petersen, 2014).

Spiritual care is considered a necessary practice and can be performed by trained physicians, nurses, health assistants and spiritual care specialists (Selman et al., 2018). However, spirituality is rarely discussed between patients and healthcare professionals, with only a percentage of 9% actually doing this (Bergamo & White, 2016). Predisposing factors for this include insufficient staff time and neglect due to lack of motivation and interest from healthcare professionals (Selman et al., 2018). The children and adolescents in this study would like to have talked about their spiritual concerns, although some highlighted fear and shame in sharing their beliefs. Other studies have also found similar results (Cotton et al., 2012; Hay & Nye, 2006).

Implications for nursing practice and further research

This is the first study about the spiritual needs of Brazilian children and adolescents with chronic diseases, and which provides a definition of pediatric spiritual care, according to participants perceptions. The authors used photographs as an interactive and innovative method for data collection on this topic. This seems to be a good strategy to be further used when studying this topic in other populations. Considering that art is a source of spirituality, this technique could be valuable in addressing such a topic with non-religious patients and in other cultures.

Spiritual care can be performed by healthcare professionals and includes aspects related to the spiritual, physical and mental dimensions of care. Empathy and patient counseling are important elements of spiritual care, as well as providing information about the disease along with connections with the sacred and with significant people. The identification of spiritual needs reinforces the necessity to include an assessment of spirituality when caring for children and family, with the aim to plan effective and individual holistic care.

This could include, for example, activities that promote an increase in the meaning of life and hope in children and adolescents with chronic illnesses. Spiritual care requires a relationship, an effective presence and is time consuming. The more healthcare team members know about family spirituality, the more adequate would be the care provided and the management of all the resources, including time.

Further research is needed using a wider range of samples and the inclusion of other cultures.

Limitations

Considering that spirituality and cultural background are closely related, including participants from only one region of the country is a limitation and caution should be taken when reading the findings. Furthermore, most study participants had a religious affiliation. Identifying the spiritual needs of non-religious children and adolescents is still a challenge, considering the predominantly religious Brazilian context. The majority of Brazilians identify as being affiliated with the Christian faith, mainly Catholicism and Protestantism/Evangelicalism (Peres et al., 2018). Moreover, it was not possible to interview children with a level of development not compatible with their age; with impaired speech; or with visual problems that impaired the visualization of the photos.

Conclusion

Five types of spiritual needs of hospitalized children and adolescents with chronic illnesses have been identified: the need to integrate meaning and purpose in life; the need to sustain hope; the need for expression of faith and to follow religious practices; the need for comfort at the end of life; and the need to connect with family and friends. These needs are fundamental to find and integrate meaning in face of the experience of chronicity and the end of life. This is done through the expression of feelings, the connection with relationships and attachment to beliefs, serving as sources of support for this moment and alleviating the suffering resulting from the chronic condition. Spiritual care was not fully provided during hospitalization, and participants explained this based on the lack of time by the professionals and by the perceived difficulty to start a dialogue on this subject.

Author contributions

Conceptualization: WAA, LCN, MV, SC; Data curation: JRM, WAA, ACABL; Formal analysis: WAA, JRM, ACABL, LCN, MV, SC, SSR; Funding acquisition: LCN, JRM, WAA, ACABL. Investigation: WAA, JRM, ACABL, LCN, MV, SC, SSR; Methodology: WAA, JRM, ACABL, LCN, MV, SC; Project administration: WAA, LCN. Resources: WAA, JRM, ACABL, LCN, MV, SC, SSR; Software: WAA, JRM, ACABL, LCN, MV, SC, SSR; Supervision: LCN; Validation: WAA, JRM, ACABL, LCN, MV, SC, SSR; Visualization: WAA, JRM, ACABL, LCN, MV, SC, SSR; Writing - original draft: WAA, JRM, ACABL, LCN; Writing - review & editing: WAA, JRM, ACABL, LCN, MV, SC, SSR.

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Declaration of Competing Interest

The authors have declared no conflict of interest.

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