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Spiritual lives of children with cancer: A qualitative descriptive study in Lithuania

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ABSTRACT

Purpose: To explore the experience and perception of spiritual lives of children with cancer.

Design and methods: A qualitative descriptive study included the collection of narratives on spiritual lives of children drawn from two university hospitals in Lithuania in the form of a semi-structured face-to-face interviews. Purposive sample of twenty-seven hospitalized children (5–12 y.) with non-terminal stage of cancer participated in the study.

Results: The final four themes emerged from across all the questions as: being normal, community, comfort and connections with God.

Conclusions: Children with cancer needed to maintain as normal a life as possible, despite being ill and undergoing treatment. Connections with family and friends were echoed in all the themes that emerged in the study. Children seemed to own their views about needing to pray or not; their needs revolved around asking for health and remission of their illness. Children diagnosed with cancer have a unique understanding of spirituality that is linked to their age, gender, and family composition. These ideas change as children develop and mature.

Practical implications: The need to explore the spiritual lives of children with life threatening illnesses from an early age is evident. Health professionals need to recognize that a child is the product of their family, their community, their culture and their spirituality. Conversations with children about what God means to them and how prayer supports them, is essential. The opinion that spirituality topic might be hardly understood or too sensitive to children is rejected by the researchers.

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Person centred care is the focus of attention in care delivery because it heralds the need for comprehensive and holistic assessment and management, particularly in long term or complex care. For children, it is not just about the child as a sick person, but rather the entire family is involved. Parents or caregivers are also the center of attention along with the child. Patient-family centred care focuses on engagement in care that is fundamental to the relationships built with patients and their families (Frakking et al., 2020). Nurses have an essential role in adopting a culture of family centered care, expressing a necessary positive attitude and a strong belief in the added value of such care

(Hengeveld et al., 2020). The ability of nurses to promote partnerships between nurses, patients and families is crucial to support high-quality health care and optimize outcomes (Cené et al., 2016).

The overall philosophy of family-centred care with a partnership approach is viewed as appropriate by both parents and nurses for the care delivery on a children's unit although the actual application requires more effort (Hughes, 2007). Practitioners report actual practices fall short of fully family centred care (García-Ventura et al., 2020). A longitudinal study with children and their family members revealed that the healthcare system remains rigid, fragmented and disjointed and focused on the biomedical aspects of care. Such design of healthcare services limits the ability to meet the increasingly complex needs of children with life-limiting and lifethreatening conditions (Mitchell et al., 2020).

Holistic care recognises that people are unique individuals where cultural and personal needs are included in care. Holistic care therefore supports a person's spiritual needs (Lalani & Chen, 2021). Spiritual care

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is a collaborative and respectful partnership between patients and health care providers (Gardner et al., 2018). It consists of assessment, counselling, support and performance of rituals which express a person's beliefs, traditions, values and practices and enable the person to access their own spiritual resources (Spiritual Health Association, 2020). If health care professionals are to tailor care according to patients' needs, the views of the patients must be taken into account (Haydon & van der Riet, 2017).

The need to further explore how care is delivered to children with complex care needs, therefore, is important. This paper explores the spiritual lives of children with cancer and acknowledges that children need care that addresses emotional, psychological, physical and spiritual needs. To help children deal with their illness and to assure the best possible quality of life and wellbeing, nurses must be proficient in all areas of care, including spiritual care.

Background

The Oxford Advanced Learner's Dictionary defines spirituality as "the quality of being concerned with religion or the human spirit or soul" (Hornby et al., 2000) as opposed to material or physical things. Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Contemporary descriptions of spirituality are associated with quality of life and wellbeing that include physical, mental and environmental elements (Juskiene, 2016). This perspective is evident in both secular and religious views of spirituality.

The development of spirituality is an individual experience which is not necessarily linked to religiosity, rather it brings together life experiences, the environment and cultural background, with many individuals finding their true spiritual self in times of crisis (Vincensi, 2019). Spirituality is expressed through beliefs, values, traditions, and practices (Damsma Bakker et al., 2018).

Lithuanians have a deep and complex history around spiritual expression (Riklikiene et al., 2016; Riklikiene, Karosas, & Kaseliene, 2018), which may impact their experience of health and well-being, as well as comprehension of links between spirituality and religiosity (Riklikiene, Kaseliene, & Fisher, 2018). Lithuania was part of the Soviet Union from 1944 until 1991 during which time expression of religion or spirituality were actively discouraged. The Soviets viewed the Roman Catholic Church as a threat since it played a prominent role in resisting Soviet rule (Alisauskienė & Zilys, 2021; Streikus, 2006). Two generations of Lithuanians were raised to worship secretly, if at all, and to avoid any expression of religion or spirituality for fear of reprisal (Juskiene, 2016). Children were encouraged in school to report whether parents, siblings, cousins or other relatives had attended Church services. Reprisals took the form of discrimination in the workplace, travel restrictions, psychological or physical punishment (Soskovets et al., 2016). In 1991, when Lithuania reestablished her sovereignty, restrictions on the expression of religion or spirituality were lifted. Over the last thirty years, Lithuanians have been reviving their relationships with religion and spirituality. This is fortunate, however, as having a strong sense of spirituality helps patients to adjust to and cope with illness and to find meaning and peace (Hess, 2018). By alleviating stressful feelings and promoting healing ones, spirituality can positively influence immune, cardiovascular, hormonal, and nervous systems (Chirico, 2016).

An ill child's relationship with God has been identified as a consistent source of comfort and strength (Clayton-Jones et al., 2016) which contributes to their wellbeing (Cotton et al., 2012). As one 16-year old girl with sickle cell disease said: "He's like the Father you can't see. He causes everything to make sense and comforts you." (Clayton-Jones et al., 2016). Young people have consistently ranked connections to self as the most important, followed by connections to others, to nature, and then to the transcendent (Michaelson et al., 2021). In Michaelson's

studies, 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'. 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, spiritual concerns of sick children and adolescents have not been fully addressed during hospitalization (Alvarenga et al., 2021). Religious and spiritual practices have been used by children/adolescents and their families and caregivers as alternative and complementary tools to deal with potentially stressful situations that emerge with cancer illness (McNeill, 2016; Omari et al., 2017).

'Children, like adults, have shifting narratives that reflect the complexities of suffering and reconciliation that emerge from both remembrance and forgetting' (Bruning, 2018). Spiritual care is crucial to the well-being of children and adolescents in times of illness and hospitalization when the goal is to provide care that is the least traumatic and the most holistic (Alvarenga et al., 2017). Children have rich spiritual lives, which are evident primarily in traumatic life situations such as illness, death and abuse (Pfund, 2000). The development of spirituality in the face of a cancer diagnosis is important, particularly in patients who require long term or palliative care because it offers comfort, hope, and contributes to a better acceptance of the disease and its repercussions (Robert et al., 2019). Children and adolescents may use spirituality to find happiness in adversity by seeking answers to the meaning and purpose in life, to improve coping processes, and as a resource to strengthen hope (Alvarenga et al., 2021; Holder et al., 2008).

Spirituality is a subjective concept, which although it is measured in research, the true sense of it cannot be adequately explored without hearing an individual's story. For children, spirituality is related to happiness, security and comfort (Crompton, 1998). It is important to note that children's ideas about spirituality change as they develop and mature. All infants have a natural awareness of suffering and a motivation to soothe suffering in others that provides a foundation for spiritual thought processes (Fosarelli, 2015). Children are open to not knowing, accepting the paradox of life, and living with uncertainty and mystery (Clayton & Aldridge, 2019). Although spirituality is part of every child's life the psychological and developmental literature usually regards the period from ages 6 to 12 as the period during which a child has the cognitive and reflective ability to perform significant developmental tasks. It is the period during which children develop self-confidence and generally have a strong sense of belief in justice (Damsma Bakker et al., 2018). Upon beginning school, children construct a perspective of one's self and one's world based upon identifying with rituals and stories pertaining to their community. By adolescence, individuals generally enter into a period where they reflect on, and expand, their world views, allowing for more mature ideologies (Werk et al., 2020).

The aim of this paper was to explore the experiences and perceptions of spiritual lives in children with cancer using narratives derived from interviews at two university hospitals in Lithuania.

Material and methods

A study was conducted in Lithuania during June 2020 and November 2021. A qualitative descriptive study included the collection of narratives about the spiritual life of children in the form of semi-structured face-to-face interviews.

An eight-question interview guide was used to examine Spiritual Quality of Life based on three areas of spiritual assessment: relationship with a higher being, with self, and with others (Kamper et al., 2010). The questions that were asked during the interview were:

1. What makes you feel happy?
2. What makes you feel bad or unhappy?
3. What helps you feel better when you are not feeling well or feeling sad?
4. Some children who are ill trying to feel closer to God. Do you try to do that? If so, how?
5. Some children pray (meditate) when they don't feel well, or they feel sad. Do you pray? If so, what do you ask for? Does prayer help?
6. Do you do anything to help your family feel better or happy? If yes, then what do you do?
7. What do you like to do in your spare time?
8. What did you do for fun this week?

Questions 1 through 3 were intended to establish rapport between the child and the researcher as well as to give children the opportunity to talk about topics and/or relationships as they emerged from the questions. Questions 4 and 5 were the heart of the spiritual interview, more directly asking respondents about their personal beliefs about God, a higher being, and prayer. Question 6 explored how a child's relationship with family impacted his/her spirituality. The last two questions, 7 and 8, moved to closure in a more lighthearted manner. Interviews were conducted in the Lithuanian language. The principal researcher [OR], a native Lithuanian speaker and fluent in the English language, accomplished the translation of the interview guide questions into Lithuanian in collaboration with the consulting researcher [LK], a native English speaker also fluent in Lithuanian.

Sample and its selection

Children with cancer (non-terminal stage, i.e., not receiving palliative care or at the end of life stage) who were hospitalized at the only two pediatric oncology-hematology centers in the county, found in two tertiary level university hospitals, participated in the study. Inclusion criteria were age (5–12 y.), diagnosis of oncologic disease for the first time, and absence of other chronic diseases.

A purposive sample of twenty-seven children participated in the interview on spiritual life experience. All were admitted to the hospital for clinical treatment with the most common diagnoses, i.e., acute lymphoblastic leukemia, acute myeloblastic leukemia, Hodgkin's and non-Hodgkin's lymphomas, tumors of the central nervous system, neuroblastoma, and other solid tumors. Children with a known developmental level below 5 years and those who had severe pain were excluded.

Conducting the interviews

Before the Spiritual Quality of Life interview, the child was assured there was no right or wrong answers. Qualitative interviews were conducted face-to-face at a prepared location (a ward or playing room). Each interview lasted 15–20 min and commentaries with each question were recorded as part of the interview process.

At first, the researchers allowed parents to be in the room while they were interviewing the children because they thought the parents might be uncomfortable if the young children were interviewed alone. Quickly it became apparent that the findings collected were not from the children. Rather, the children looked at their parents, who then suggested answers. Parents were then asked to get a cup of coffee and sit in the hallway so that the children could see them. The parents did not object and then the children could be interviewed in a separate, but safe environment. There was no remuneration or gifts for the participants or their parents for agreeing to be part of the research.

Children were interviewed face-to-face by two researchers who were practicing pediatric nurses in two different study sites. One of the interviewers took a managing role in the same hospital but did not provide direct care to the children. Visiting the department, the interviewer was directed to patients that met the inclusion criteria by

nurse managers. The second interviewer was an experienced nurse that took care of some of the children who took part in the study. These two interviewers were the same people who recruited the participants and received the informed consents from parents.

Ethical considerations

The study was approved by the Committee on Bioethics of the Kaunas region (12th July 2019; No. BE-2-6). Before inviting the children into the interview, the researchers talked to the families to find out if the children would be available to talk about their spiritual lives. In addition, children were subsequently consulted about their desire to participate in the study. The informed consent was signed by parents while the children were included in age-appropriate discussions about the study and provided their verbal consent. The Committee on Bioethics of Kaunas region supported interviewing children alone and commended the researchers for including the children in the consent process.

Analysis methods of children's stories

The interviews were recorded and then transcribed by the researcher, a doctoral student. All transcripts were stored in a personal computer protected with a passcode. The respondents were coded by a specially created identification number. Names or other personal details that would allow identification of specific respondents were not recorded in the data file.

Interview narratives were first collated by question and translated by the bi-lingual research consultant [LK]. The use of a bilingual researcher proficient in not only both languages, but also immersed in both cultures, was important to accurately translate children's thoughts, metaphors and themes rather than strictly words. Further the translation of narrative was independently checked for consistency by two researchers, native in Lithuanian and fluent in English.

Thematic analysis was used to identify themes and patterns in the narrative (Braun & Clarke, 2006; Braun & Clarke, 2019). Increasingly, the analysis of interviews that draws out themes and patterns is being seen as essential to understanding the patient journey in illness and care (Braun & Clarke, 2019; Haydon & van der Riet, 2017). Respondents' quotations confirmed and exemplified each theme.

Thematic analysis consisted of identifying themes and patterns within the text, using a systematic, step-wise approach (Braun & Clarke, 2006). The researchers first familiarised themselves with the narratives, then coded specific features in a systematic fashion. Once a set of themes was created, further review collated them into main themes, and if necessary, subthemes. The narrative text itself was the empirical finding that demonstrated the theme (Braun & Clarke, 2019; Haydon et al., 2018).

Credibility of the study was addressed through researcher triangulation and peer debriefing of initial codes and preliminary analysis. Also researchers reached consensus on themes and their interpretations (Nowell et al., 2017).

Study trustworthiness

Beal (2013) stated that "a collection of narrative accounts is an opportunity to apprehend the differences and diversity of individuals and their storied experiences." The key to narrative analysis is to have a distinct reason for its use. Thus, the question for the research must be clear to guide the analysis (Haydon & van der Riet, 2017). Themes are used to uncover significant findings. Transcripts of the multiple interviews were combined to form one large narrative which was then examined for themes and patterns. The two researchers carried out the analyses separately, with support and consultations from the third researcher. The preliminary results were then discussed by all researchers to establish trustworthiness.

Table 1
Social-demographic characteristics of participants.

Code	Age in years	Gender	Place of residence	Birth order in a family	Parents live together
V1	11	m	urban	1	Yes
V2	11	m	urban	1	No
V3	12	m	urban	1	Yes
V4	11	m	urban	2	Yes
V5	12	f	urban	1	Yes
V6	10	m	urban	2	No
V7	10	m	urban	2	No
V8	9	f	urban	2	Yes
V9	11	m	rural	1	Yes
V10	12	f	urban	1	Yes
V11	11	m	urban	3 and higher	Yes
V12	10	f	urban	1	Yes
V13	8	m	urban	1	No
V14	7	f	rural	2	No
V15	6	m	urban	1	Yes
V16	11	m	urban	1	No
V17	5	f	rural	1	Yes
V18	12	f	urban	1	Yes
V19	7	m	rural	3 and higher	Yes
V20	11	f	urban	1	No
V21	7	m.	urban	2	Yes
V22	11	f	urban	2	Yes
V23	11	m	urban	1	Yes
V24	10	f	rural	2	Yes
V25	7	m	urban	2	Yes
V26	6	m	urban	1	No
V27	5	f	urban	1	No

Findings

Findings from the semi-structured interviews were summarized and synthesised and presented as a narrative using identified themes according to the stepwise process by Braun and Clarke (2006).

Twenty seven children agreed to explore their experience and perception of spirituality expressing their views freely. Table 1 provides demographic information about the children who participated in the semi-structured face-to-face interviews.

The final four themes that emerged from all the questions were:

- Being normal
- Community
- Comfort
- Connections with God

Some themes had several subthemes, which will be described more fully with illustrations from narratives.

Being normal

Subthemes included *activity* and *physical differences*.

Play was a dominant theme throughout the narrative – having friends come to visit whilst in the hospital was important; making friends with other sick children was also important. Having presents, toys and activities helped to ease the emotional burden of being sick and hospitalized. Children stated they engaged in a wide range of activities from reading to jewelry making, Lego, and board games. Children constantly referred to the fun they had when able to play with friends, even when hospitalized:

I am happy when I am with my friends, doing what I like, i.e., reading books, swimming, skateboarding, dancing and listening to music. (V5)
I like to draw, paint with watercolors. I also string jewelry from small stones. (V18)

Being able to do 'normal' things was important, for example walking outside and playing on the computer. These activities were linked to feeling normal and not having to dwell on illness:

Walk far outside, especially in nature. Play computer games. (V2)
Walking outside calms me down. (V7)

Gifts, presents or other surprises were important for the happiness of children at different ages:

Getting presents. (V21); <... > a lot of new cars. And all kinds of other toys. (V21)

Some kind of surprise. For example, when they say there is nothing delicious, but then (pulls chocolate out of the drawer). (V13)

Unhappiness was expressed when they were unwell, did not know how to spend their time, got bad news from the doctor and if they had to go back to the hospital:

I'm unhappy when I'm sick. (V5)

When nothing goes right. <...>. (V16)

When the doctor delivers bad news. (V9)

I am unhappy when they tell me I have to go into the hospital again. I always stay a long time. (V21)

When I can't find anything to do to pass the time. (V3)

Children talked about *being different* from other children which increased their feelings of unhappiness and isolation when they were out of hospital. They were often not able to join in games, and that because of physical differences brought about by their illness, such as loss of hair, they felt like outsiders. Girls were more concerned about physical differences than boys, and those living in an urban location with both parents:

Because I can't do what others do. Go everywhere, joke around together, send funny videos, Tik Tok. I don't like using the camera when I'm with my friends. I don't like them staring at me. I look awful with my moon face. Mother says it only looks that way to me and all my friends are nice. But in reality, no. (V10)

Because I don't have hair, no eyebrows, no eyelashes. Nothing. Then it seems everyone is staring. (V18)

Older children tried to stay optimistic and positive despite the circumstances:

Everything makes me either feel good or the negative is so insignificant that I don't notice it. (V3)

But I am always happy. Even though sometimes all kinds of things happen. (V23)

I do something to take my mind off anything bad. (V24)

Community

This theme had two subthemes: *consideration for others* and *being together with family and friends*.

Overall, children's views revolved around family, friends, and inclusiveness; not feeling isolated. Their responses showed a need to make sure others were happy around them, knowing that people were sad because they (the child) were sick, but at the same time, needing the affirmation of love from friends and family. So, on the one hand, boys and girls of different ages were *concerned for others'* welfare, but also their happiness was evident when happy family and people were around them:

When others are happy, so am I. (V16)

When I am, or the ones close to me, are successful. That's when I am happiest. I show interest in them. (V10)

I try to clearly state my needs and emotions and show them how much I love them. (V3)

In contrast, children spoke of how sad they were when family members and others were sad:

(Unhappy) When my parents are angry or sad. (V25)

When someone cries. Then I am also sad. (V15)

References to family members hugging them was common, as was being brave and strong for their family by not showing how unhappy they were. Boys 10–11 years old, living only with their mothers were much more likely to demonstrate empathy and protective behavior toward their families

It helps when mother hugs me, my sister hugs me. (V8)
When mother hugs me and says it will pass soon. And it passes. (V12)
I try to be in a good mood. To not make them [family] more sad. (V18)
I am strong. I have to be strong and brave...my mother says so. I want her to be happy. So I stay strong. I am always in support of my family (makes a fist, smiles). (V16)

When at home, children were very much altruistic and did different things for their family to feel better: they cooked, made others laugh, helped and supported each other. They behaved in everyday life situations to increase their parents happiness:

I obey my parents, don't argue with my brothers. (V19)
I ask them [parents] to make up if they get into an argument. I try to be good. (V25)
I am good, listen to my mother, put away my toys. (V27)

Sometimes the children intentionally acted to generate positive reactions from their parents:

I try to eat more because we get into arguments that I don't eat enough and I weigh less. My mother smiles when my plate is empty. (V20)
I try not to show them I'm sad. I ask about how it is going for them, I show interest in them. (V10)
I try not to cry when I am stuck. Then everyone is happy, praising me. (V12)

Several children were proud that their families were already happy and additional efforts were not needed:

Well, they are happy already (show a photo of sister smiling on the phone) I don't need to do anything. (V11)
I think my family is already happy. (V21)

Being together meant that friends and family visited them and that made the children happy, particularly when they brought presents that resulted in activities and fun:

I am happy when it is fun, <...>, when the whole family is together, laughing and talking. (V8)
The happiest day is when father comes. Then we laugh a lot. He is very funny, plays a lot of jokes (chuckling) (V12)
<...> with family we had a nice dinner, with family we watched movies. (V5)

Calling friends on the phone and being able to talk to them was also important:

Talking to my best friend. When I talk – I am instantly happier. Everything doesn't look as bad. We laugh at everything. We laugh a lot. We wait to see who will hang up first. We talk a long time. Even up to an hour. (V10)
When someone visits, calls with video. (V19)
Talking to people close to me. You talk and it's better. (V16)
This week, I spent some time with a friend from another unit. (V5)

Pets were referenced several times, providing children with unconditional love and caring:

I really miss my dog. He is very sweet and sleeps on my pillow. Boltas (dog's name) is my buddy. (V12)
I am happy when I am successful. When I am surrounded by animals. (V7)
My Bear (dog). He licks my whole face and also my hands. (V26)

Comfort

Comfort was physical in nature. This theme had two subthemes: *not having any pain and having a remission of symptoms* which allowed them to feel better.

Pain and suffering caused discomfort and made children unhappy and sad:

(Unhappy) When I'm weak or in pain. (V1), When it hurts. (V7)
When it hurts and medicine doesn't help. (V26).

Unhappiness and feelings of isolation were increased with pain from constant blood tests and poor results, fatigue and increased length of hospital stay:

I am tired and want to go home. (V13)
When I feel worse and tests are worse because then I have to stay here longer. (V24)
When it looks like I am going home, but the tests are worse. And I have to stay. Then it really gets on my nerves. (V11)

There was no reference to surgery, chemotherapy, or other treatments that these children inevitably were exposed to. Comfort was mainly perceived as being able to avoid hurtful procedures and suffering from the daily exposure to hospital life:

When the medicine works, and the catheter doesn't have to be changed so often. (V20)
(Makes happy) Medicine, when it's injected. Almost always makes it better. (V11)

Children were happy with *remission of symptoms*, feeling better and being discharged, and with the possibility of sleeping in their own beds:

When blood levels increase. Then I am happy. (V11)
When I am finally discharged from the hospital. (V22)
When the doctor says the tests are better and I can go home. Sleeping in my own bed. (V18)

Nurses and other health care workers were not central in discussions. Comfort was not having something done to them that hurt. Only one nurse was referenced as not hurting the child when taking blood.

When they say they need tests every time they draw blood. It hurts...it always hurts. Only Eli (nurse) does everything gently. Others make it hurt. I don't like that. (V14)

Connections with god

Children considered connections with God in abstract terms. Several children indicated that they were not really sure if God existed and, if so, how connections with God could really be made and could help them:

Sometimes I wonder if there is a God, but I don't know, I don't do anything. (V20)
I don't believe in any gods, that's not acceptable to me. (V3)
I don't know how to pray? What? What does it mean to be closer to God? Don't you have to go to church for that? Pray. Maybe then I'll be closer. I don't know. (V15)
I don't do anything; I didn't know that you can. (V25)

Several said they did not know how to pray or they do not pray and their family were not church-goers:

No, I don't need that. Somehow, I figure it out. (V11)
My family does not believe in God. (V23)

Some children, however, indicated that they prayed in their mind and felt that it did help. For these children it was personal and not shared with others. Their prayers revolved around their need to be healed and to feel well again:

I pray silently, only in my thoughts, that I would get better and go home. [I pray for] Health. For my family's success. (V4)
I pray, but not every day, sometimes I forget. I ask to get better quickly and be able to more frequently see my friends, mother, father, etc. And that everyone would do well and be healthy. (V22)
Sometimes [pray]. To get better. Mother says that prayers help. Grandmother prays for us all. She says that herself. (V16)

One child indicated he prayed for everyone, and not necessarily for only himself.

I pray before going to sleep. I ask that everyone in the world alive and dead would sleep well and be happy in the morning. Prayer helps me, but I am not sure it helps others. (V8)

Other children shared their doubts about how much prayer can help, if at all:

Yes, I pray. I ask for health. Sometimes it helps, sometimes it doesn't. (V1)
I only know the „Hail Mary,“ don't know if that prayer works to ask for something. (V20)

The question about God and praying was the one that deeply touched the children. A 10 year old boy was very emotional sharing his prayer that the whole family would be alive and together, including himself (but not mentioning himself directly):

Yes. I can't say (tears). But I want to say (tears). That my whole family would live (tears). (V6)

In some cases children were not consciously aware of the connection with God or did not call their thoughts and requests as praying even though they intuitively did:

I don't do anything. But in my mind, I ask. (V18)
In my thoughts I talk. I ask that it would get better, I want to see my friends. The ones not from the hospital. The other ones. It helps. (V14)
In my mind, I think I will get better. I believe that there is a God. (V9)

Beside the family influence, religious teaching at school helped young children develop their understanding about transcendence and esoteric relationships:

Sometimes I talk to God in my mind, I pray, the religious teacher said that He listens. (V22)
I know a prayer. During class (first communion) I was taught it. (V12)

At the end the researchers asked children about their favorite activities during spare time and what they did for fun recently, while hospitalized. This question transitioned from the previous discussions about existential and inner thoughts and emotions to the meaning of everyday life for these children and their needs.

A wide range of activities, by age and gender, were favorites for the children: reading, drawing and painting with watercolors, playing computer games, sculpting with clay, making Origami, riding bikes, watching movies, playing with pets, etc. During hospital stays children corresponded with friends, spent time with family and hospital mates, and participated in unit events:

This week, I spent some time with a friend from another unit, with family we had a nice dinner, with family we watched movies, and I read an interesting book. (V5)
I finished reading a book. Finally, finally because it was very thick. I thought I wouldn't finish it for a hundred years. (V10)
Yesterday I had my photo taken with dogs (pet therapy on the unit). (V9)
The noses were here („Red noses“the doctor clowns) We laughed a lot. I waved to them. Previously, they would come into the rooms, it was more interesting. (V14)
I got pizza brought to me. At least I got to eat well for once (smiling). (V11)

Discussion

This study explored how children viewed spirituality when sick and how they included it in their lives during crises. What emerged was far more than a need for a spiritual connection, but rather, the need for children to express their spiritual thoughts and feelings within a supportive environment of individualized care. Health care workers must be able to respect a person's individual needs with compassionate and non-judgemental approaches (Byrne et al., 2020). Children needed to maintain as normal a life as possible, in which family, friends and medical staff were central to achieving normalcy. In this study, spirituality centered around feeling well and getting better in order to return to normal lives and home environments. Kamper et al. (2010) found similar results regarding ill children and a need for normalcy, family ties and hobby oriented activities.

Chronic oncological illnesses in children affect normal activities, require frequent hospitalisations and are prolonged, from the acute phase of illness, extended treatment, and then followed by death or survivorship. Each phase presents its own set of stressors and challenges that affect the child and the family (Compas et al., 2012). Children cope with hospital stays by converting them to something that they can relate to in daily life through connections with family, friends, play and imagination. In this study, happiness from everyday things and the ability to have fun made children feel better and made life with an illness easier to deal with. Connections with family and friends dominated all the questions and the resultant themes of the study. Connections were also evident with their pets.

Children also wanted to be involved in what was happening around them, so conversations with hospital staff and inclusion in explanations about their condition was important. Hence, including the child in family discussions is essential (Jepsen et al., 2018). In this study, healthcare workers were not central to any discussion, except when giving bad news or performing medical procedures. Jepsen et al. (2018) noted that children wanted to be on good terms with the hospital staff, even to the point of needing affirmation from them, even if they did not fully understand what was happening to them. In terms of providing person-centred care, the importance of child-staff relationships is clear and it is important for this aspect to be part of any professional development program for the care of children. Jepsen et al. (2018) contended that health professionals were equally important in maintaining the child's integrity, ensuring that the team is the child, family and health care professionals.

Children also wanted to be children, even when sick, with friends, family, toys, and fun activities being central to this status (Jepsen et al., 2018; Kamper et al., 2010; Pehler & Craft-Rosenberg, 2009). Friends were also spiritually important as they provided a sense of normalcy (Damsma Bakker et al., 2018). Family, toys and animals were important for the participants of this study, as they were in other studies (Nash et al., 2013). The use of pet therapy in children with autism spectrum disorders has been well defined in reducing stress and disruptive behaviors. For any ill child however, the ability to connect with a pet who provides unconditional love engenders feelings of inclusion and security (Berry et al., 2013). In some countries, including Lithuania, pet therapy forms part of the hospital experience (Hinic et al., 2019) and should be introduced to more healthcare facilities.

In terms of spirituality, participant responses were related to family and friends. Their views of God and prayer were more abstract. Some children in our study identified prayer as supporting their journey through illness. Their needs revolved around asking for health and remission of their illness. This was evident when they used prayer to ask God for strength and comfort in lived situations (Rossato et al., 2021). Prayer became a way for sick individuals, their families or caregivers to communicate with God and request improvements for what they were going through, as described by Moore et al. (2020). Ill children pray even if they feel prayer does not help but makes them feel better (Kamper et al., 2010; Wilson et al., 2011). As in the study of Barton

et al. (2018), answers about praying also reflected concern for other loved ones. Several children in the study did not believe or doubted that prayer or being close to God were important and helpful. The youngest children did not even know what it meant to be close to God and how they could achieve this.

Family members can influence children's perceptions of religion, spirituality, or worldview (Hexem et al., 2011). In addition, school, media and peers (Moore et al., 2012), and hospital and health-care professionals can influence the spirituality of children and adolescents.

Although family values clearly had an influence on children's views, this was not often verbalised. Children seemed to own their views about needing to pray or not. For those who did pray, it was personal, in their mind and not shared. These findings were identified in other studies as well, where children were found to own their views on God and prayer (Kamper et al., 2010). This suggests that although external influences might have shaped their thinking, their use of prayer and their relationships with God were their own.

Practice implications

The important outcome from this study was that holistic and family-centred care is essential for children with a life threatening or chronic illness. In turn, health professionals need to recognize that a child is the product of their family, their community, their culture and their spirituality, in addition to accepting that they are children with children's needs, as different from adult patients. Health professionals also need to recognize the importance of spirituality through the eyes and experience of a child. Lithuania is a religious country and, therefore, these conversations should be natural for everyone involved. Nurses in particular, being the closest and most constant health professional in a child's life, should be prepared educationally and professionally, to have these conversations with children and families. Nurses need to permit children to express their views, uncover meaning to increase their wellbeing and capacity to cope with chronic illness.

Initially, the researchers were concerned that the topic of spirituality, which is very personal and specific, would be perceived as an inappropriate theme to discuss with parents and children. However, both parents and children viewed the spirituality theme as valuable and willingly participated in the study. In Lithuania, spirituality is still closely tied to religion and although more and more younger adults are not religious, they remain spiritual. Religious traditions such as going to church, accepting sacraments and belonging to parishes, are less characteristic of the younger generation. However, this generation embraces spiritual well-being, balance and strength from other perspectives such as yoga, meditation, and emotional intelligence. The researchers feared that parents would perceive the study to be about religion and encouraging religiosity, but the parents' reactions were supportive. One mother even returned on another day to thank the researcher for the study and for the conversation with her son. According to the mother, she did not expect her son to even think about religion and spirituality, much less that these were important to him. The mother explained that the interview was like psychotherapy as she had the opportunity to talk for a long time with her child after the researcher left them. This case supports the findings of Woodgate and Degner (2003) that most families become closer from the experience of cancer. Unity of the family was just as equally significant to children and families as was getting through the illness experience. So, the need to further explore the spiritual lives of children with life threatening or chronic illnesses from an early age is evident. The researchers rejected the notion that a topic such as spirituality might not be understood or too sensitive for children. The interviews with children from 5 to 12 years old revealed that young patients were capable of clearly expressing their feelings and thoughts in relation to what they wanted, needed, valued, expected and experienced – positive as well as negative or even sacred feelings and thoughts.

Limitations

First, the interviews were conducted in the Lithuanian language and narratives were analysed and then translated into English. Often with qualitative exploration of personal experience, language and wording of thoughts and opinions are inevitably expressed in specific metaphors, slang and indirect meanings that might be partially or wholly lost during translation. To compensate for this shortcoming one author was a bilingual researcher, not only fluent in both English and Lithuanian, but also immersed in both cultures. The advantage of such a researcher was to more accurately and fully reflect the meaning of the children's thoughts and perceptions. Second, the instrument used was simple and concise, but even for a limited time, conversation could be frustrating and difficult for sick children undergoing treatment. Therefore, there was always a possibility that the circumstances of the interview and the child's well-being could have resulted in abbreviated or incomplete narratives.

Conclusion

The study participants needed to maintain as normal a life as possible, despite being ill and undergoing treatment. Staff, family and friends were central to achieving a semblance of normalcy in daily life. Connections with family and friends were echoed in all the themes that emerged in the study. Children needed to feel they were a part of a family as well as having friends, both in the hospital and outside of the hospital, to feel connected to normal lives.

Children diagnosed with cancer have a unique understanding of spirituality. Their ideas about spirituality are linked to their age, gender, and family composition. These ideas change as children develop and mature. In this study, spirituality centered around feeling well and getting better, but not just for the children themselves. Despite being sick, children also demonstrated emotional protective behavior toward their families. They would mask their unhappiness or sadness and behave to help their loved ones to also feel better. This was especially true for boys living with only their mothers.

This study showed that children are not too young to understand spirituality and to be able to discuss what it means to them in their own particular way. The recognition and assessment of spiritual health and wellbeing is the first step in addressing spiritual concerns in care for children, not only adults. Health care professionals can and should become better versed in what spiritual care means to the children they care for.

Declarations of Competing Interest

None.

CRediT authorship contribution statement

Erika Juškauskienė: Methodology, Investigation, Data curation, Formal analysis, Writing – original draft. **Laima Karosas:** Formal analysis, Writing – review & editing. **Clare Harvey:** Formal analysis, Writing – review & editing. **Olga Riklikienė:** Conceptualization, Supervision, Writing – review & editing.

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