



Spirituality among parents of children with cancer in a Middle Eastern country

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ABSTRACT

Purpose: Family caregivers of children with cancer face emotional, psychological, and spiritual challenges coping with their child's illness. For ensuring comprehensive multidisciplinary pediatric care, there is a need to understand and define what spirituality means for them in relation to their child's illness. The purpose of this study is to understand the meaning of spirituality for parents of cancer patients in Lebanon.

Methods: This qualitative study followed the Heideggerian interpretive phenomenological method. Through purposeful sampling, 11 parents (mother or father) of children with cancer receiving treatment at a tertiary care center in Beirut, Lebanon were interviewed. Data were analyzed following the hermeneutical process as described by Diekmann and Ironside (1998).

Results: A constitutive pattern and overarching theme, "spirituality is a two-level relationship. It is a relation with God and with people. It is the act of receiving and giving back" and five major themes emerged from the data. These were "Being there for me; " "Connectedness with other parents is a blessing and a torment; " "The power of knowing; " "Communication with Unknown" and "Spirituality is not religiosity".

Conclusion: Lebanese parents of children with cancer defined the elements of their own spirituality. Relational aspects dominated and communication was an important factor. Implications for practice: This is the first study in the Middle East to address the meaning of spirituality in this population, and would pave the way for a customized palliative care program and integrative approach to patient care.

1. Introduction

Spirituality is usually defined as a person's search for the meaning of life and death, search for purpose, for connectedness to self, to others, to nature, and to the sacred or significant; it might also involve seeking transcendence beyond life. It is a complex, dynamic, and multidimensional concept – not necessarily with a religious connotation – and is an integral part or need of the human being (Asgeirsdottir et al., 2013; Steinhäuser et al., 2017; Penman et al., 2013). The concept of spirituality is thought to be culture-bound, but there are in fact variations among people within the same culture, sometimes based on different philosophical perspectives or past experiences (Asgeirsdottir et al., 2013; Steinhäuser et al., 2017; Penman et al., 2013; Nemati et al., 2018). As opposed to being coupled with religion and faith in God, spirituality is now being assessed more as a multidimensional concept. The operational definition of spirituality and its dimensions need to be explored and defined for each population. As most studies measure the

one aspect related to a specific context, they tend to lack the multidimensional measurement of all spirituality domains. Thus, they cannot be generalized or applied in populations with different cultures or in families of different types of patients (Steinhäuser et al., 2017). Although the relationship between spirituality and health remains a subject of much debate, spirituality does affect at the very least the way patients deal with illness, decision-making, and the expression of pain (Aslakson et al., 2017; Astrow et al., 2018; Gardner et al., 2017; Nicholas et al., 2017; Hexem et al., 2011). The conceptualization, definition and measurement of spirituality is important in assessing its relation to health outcomes (Steinhäuser et al., 2017).

Spirituality in caregivers and family members of patients with a severe illness is gaining the attention of researchers given the role that caregivers play in the illness and healing process (Steinhäuser et al., 2017; Nemati et al., 2018; Aslakson et al., 2017; Gardner et al., 2017; Nicholas et al., 2017; Selman et al., 2018; Delgado-Guay et al., 2013).

In the case of pediatric cancer, the life of the whole family is

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affected and parents may turn to spirituality and focus on positivity to cope with the fear and powerlessness that they can experience with their child's illness (Nicholas et al., 2017; Hexem et al., 2011).

Studies indicate that spiritual needs differ among parents of children with cancer and should be individually assessed and addressed in the child's routine care (Knapp et al., 2011). In fact, Wiener et al. (2016) revealed that spiritual faith increased in all parents having a child with cancer while health behaviors declined (Wiener et al., 2016). Positive spiritual coping can be a predictor of benefit finding in parents of survivors of childhood cancer (Gardner et al., 2017).

Nicholas and colleagues examined parental spirituality in parents of cancer patients with a poor prognosis, and found that parents of children with life-limiting cancer reported spirituality as religious beliefs and practices, notions of a higher being, meaning-making and relationships.

Parents with deeper spirituality had greater acceptance of their child's condition, experienced emotional decompression, and benefited from the support of their faith community (Nicholas et al., 2017).

Lebanon is one of the most mixed countries of the Arab world in terms of cultural and religious diversity. Its population, composed of a combination of Christians and Muslims, has historically been a cultural connection between the East and West. The Christian (Maronite) and the Muslim (Druze) communities are groups mainly specific to Lebanon. In Lebanon the meaning of spirituality is not culturally well-studied and defined. A belief about the Lebanese is that they are generally superstitious and seek to ensure additional “heavenly” support for health problems. Lebanese Christians (and many non-Christians) visit shrines of the Virgin Mary and other saints and make vows to give gifts or other contributions if their significant others are healed (Adib, 2008).

Saad et al. in evaluating the quality of palliative care provided to children at the Children's Cancer Center of Lebanon during their last month of life reported parents' need for spiritual support, namely faith and prayer (Saad et al., 2011). Whereas, in another study conducted by Al Gharib et al. (2015) involving 85 parents of children with cancer at the same center to evaluate the quality of palliative care provided to the children using the Needs-at-End of Life Screening Tool concluded that spirituality was high among all participants (Al Gharib et al., 2015). It is worth noting that spirituality is an important dimension of palliative care and prior to this current study there was no clear understanding of what spirituality meant to Lebanese parents of a child with cancer nor to the people of the region.

Lebanon, just 10,452 square kilometers in area, is between the Mediterranean countries and the Arabian Peninsula. Because of its Mediterranean coastal location, the country has a rich history of religious and ethnic diversity, in addition to political turmoil and wars. The total population of Lebanese people worldwide is estimated at 13 million to 18 million. Of these, the vast majority.

8.6 to 14 million, are in the Lebanese diaspora (ie, in countries around the world, outside of Lebanon), and about 4.3 million currently live in Lebanon itself. Understanding the meaning of spirituality for Lebanese parents of a child with cancer is important for the parents residing in Lebanon today and also for parents of Lebanese origin living in the diaspora.

The purpose of this study is to understand the meaning of spirituality for parents of children with cancer in Lebanon without imposing any a priori categorization that may limit the field of inquiry. This would be the first research in the Middle East to address the meaning of spirituality in the population and would pave the way for a customized palliative care program and integrative approach to patient care.

2. Methods

Design: This qualitative study followed the Heideggerian interpretive phenomenological method described by Diekmann and Ironside (1998) seeking to uncover common meanings of spirituality for

parents of children who have cancer. In contrast to the descriptive phenomenology the 'interpretive/hermeneutics approach' goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices. These meanings are not always apparent to the participants but can be gleaned from the narratives produced by them. The focus of a hermeneutic inquiry is on what humans experience rather than what they consciously know is used to examine contextual features of an experience in relation to other effects such as culture, gender, of people or groups experiencing the phenomenon. This permits researchers to reach a deeper understanding of the experience, so that caregivers can derive necessary knowledge needed to tackle such clients' needs.

2.1. Trustworthiness of findings

Member checking with participants and peer debriefing among researchers were performed for credibility. Lincoln and Guba (1985) trust that a study meets transferability when findings can be applied in varied settings and the rich database that allows transferability judgment possible on the part of potential applier is present. In this case, the database comprised verbatim excerpts from the interviews (Lincoln and Guba, 1985). Dependability was met through within-method triangulation with the use of field notes and recorded interviews. An independent analysis of data by two researchers followed to validate themes, and confirmability was secured with an audit trail (Kennedy, 1995).

2.2. Sample and setting

Following the principles of phenomenology, this study used purposeful sampling in which participants were contacted based on their genuine knowledge of the phenomenon and their readiness to share that knowledge (Diekmann and Ironside, 1998; Cohen et al., 2000). Information-rich cases were pursued using maximum variation sampling related to gender, stage of the disease, religion, and socio-economic and educational background. Recruitment started with the first author presenting the study to the Nurse Managers (NMs) of the Inpatient and Outpatient units of the cancer center. As potential participants were identified, the NMs contacted them, invited them to take part, and presented the study. A mutually convenient time was scheduled for the interviews, which took place at the center in a private room at the parents' request. Institutional Review Board approvals were secured from the Lebanese American University and the American University of Beirut in addition to special permits to enter the center. Anonymity and confidentiality were maintained through the use of pseudonyms and by keeping all records in a locked cabinet.

2.3. Data collection procedure

Audio-taped, in-depth and semi-structured interviews were conducted in Arabic by the first author, who is competent in qualitative data interview methods and articulate in both written and oral Arabic and English. Efforts were made to make sure that participants were the main speakers, while the interviewer assumed the role of listener and facilitator without controlling the interview (Patton, 1990). Participants were interviewed twice. During the first interview (40–50 min), the interviewer used the first 10 min to confirm that the participant understood the study purpose, the informed consent and was willing to participate. The second interview (30–40 min, two weeks later) was used to authenticate the initial analysis and clarify the meaning of previous statements (member check). It is worth noting that in all second interviews there was complete authentication of data analysis from participants. Field notes taken during the interview described observations made by the interviewer regarding participants' body language, tone of voice, distractions, and changes in physical condition of comfort (Diekmann and Ironside, 1998).

Interviews started with a broad question “What does the word spirituality mean to you?” and asked for examples that elucidated the accounts. Probing techniques were used to produce further explanation, an approach generally used in phenomenological interviews (Streubert and Carpenter, 2010). To limit socially pleasing answers, the interviewer made it clear that she was interested in the participants’ personal thoughts and ideas (Kennedy, 1995). Interviews were carried out until saturation occurred and no new ideas could be extracted (Diekelmann and Ironside, 1998). Each was transcribed verbatim by an experienced transcriptionist and verified for exactness by the first author.

2.4. Data analysis

Data were managed using QSR NVivo 9 (QSR International, 2017). Data analysis commenced after the first interview to allow for concurrent data collection and analysis. Every transcript was translated into English and then back-translated into Arabic for accuracy by two different bilingual professional translators (QSR International, 2017; Brislin, 1970). Two bilingual team members were careful to preserve the conceptual equivalence of the interviews by checking the translation and back translation (Maneesriwongul and Dixon, 2004; Larkin et al., 1998). The English version is a technically and conceptually correct translated version of the interviews.

Two researchers experienced in qualitative research independently analyzed transcripts and identified themes, and then met and compared notes. Both researchers had almost similar results.

Analysis followed the seven-stage hermeneutic process explicated by Diekelmann and Ironside (1998) that allowed for clarification and validation and helped to ignore unverified meanings.

The hermeneutic circle includes incessant analysis of the whole and the parts of the text, and confirmation that interpretations are grounded and focused through constant reference to the text (Al Gharib et al., 2015). At the start of each interview and analysis cycle, the researchers used reflexivity to avoid reaching an interpretation prematurely. Reflexivity plays a central role in the researcher’s attempts to keep a check on their preconceptions (Finlay, 2008) (Table 1).

3. Findings

Mothers and fathers (9 mothers and 2 fathers) of 11 children with cancer participated, with a mean age of 36 years. Their experience with the disease spanned 3 months to 6 years with cases ranging from first-time diagnosis to relapse conditions (Table 2). All parents had some difficulty at the beginning with the grand tour question that entailed portraying spirituality. It was not until they had started relating their experiences and feelings that a meaning started to emerge. This first study, elucidating the meaning of spirituality of Lebanese parents of a child with cancer, yielded the constitutive pattern “spirituality is a two-level relationship. It is a relation with God and with people. It is the act of receiving and giving back” that epitomized the all-embracing and connecting pattern across all emerging themes.

The clear, and pure revelation of the meaning of spirituality for them had them in tears or shaken during both interviews. This reaction

might be due to spirituality unfolding slowly when parents began narrating their experiences, and how they gradually pieced together the elements that defined their spirituality. This pattern was best reflected by Nadia, a 33-year-old mother of a 6-year-old girl who has optic nerve glioma diagnosed 4 years ago and experiencing her third relapse:

“... now I can say that we have spirituality up and spirituality on earth ... the relationships between people constitute spirituality. Spirituality is the rapport between people ... and the rapport with God. It is the warm connectedness that gives you inner peace from inside”

Theme 1: Being there for me.

While talking about their experience with their children, parents highlighted that the support received from their surroundings made them feel strong and somewhat serene, which helped them to cope with their child’s illness. They described supportive relationship as an important element of their experience. Ghada, mother of a boy diagnosed with ALL and in relapse said:

“... the family bonds between me and my sisters are very strong. The emotions are very important. It is very important to feel that there are people who are feeling your pain. This existential relationship is important. My family supports me a lot while I am here. They take care of my other children. They cook for me and supervise my children’s studies. This makes me feel more relaxed and at peace.”

While talking about her family support Ghada had tears into her eyes and her voice softened. The presence of her family members around her without even asking for their help gave her strength. This surrounding presence gave her strength and internal peace.

Marie, mother of a boy diagnosed with T cell lymphoma one and a half years ago mentioned:

“... all my parents and friends are around me. They cook for me and they look after my other children. Every time I come here, I have a friend coming with me for support. At work they told me feel free to come and go as I wished ... All this made me feel strong inside. This feeling that others are concerned for your wellbeing is very important. It creates a feeling of tranquility inside you; it gives me power. I think this is spirituality ...”

Also Marie highlighted the importance of being surrounded and mainly by friends. She spoke very highly of the unconditional support received from her friends and she insisted on the idea that they are offering support without asking for it. This voluntary support as she call it created an internal tranquility that she called spirituality.

Bob, father of a boy diagnosed with ALL a year and 4 months ago said:

“... the care and support that this center is providing means a lot. Without them I would have felt lost. This center does not differentiate between people according to religion or background. This made me feel secure, and spirituality is how you think or feel from inside. The staff are very supportive. They explain everything to me which makes me feel tranquil inside ...”

Table 1
Data analysis process.

Stage	Data Analysis
1	Each researcher independently read the text to gain a general understanding of the parents’ explanation of spirituality
2	Each researcher identified common meanings of the text and supporting excerpts
3	Researchers compared interpretations during meetings to attain consensus, reaching further clarification by returning to the original text
4	Researchers reviewed all the texts to link the themes
5	Researchers identified a constitutive pattern that illuminated the relationship among themes across all texts
6	Participants authenticated the themes in the second interview
7	The summary was written using quotes as validation for readers

Table 2

Demographic information about parents of children with cancer and child's diagnosis and time since diagnosis.

Pseudo name	Age /Years	Gender	Role	Level of education	Child diagnosis	Time since diagnosis
Lea	45	F	Mother	Intermediate	ALL	3.5 years (relapse)
Mira	30	F	Mother	Secondary	AML	2.5 months
Nada	35	F	Mother	University	ALL	4 years (2nd relapse)
Maya	32	F	Mother	University	ALL	2 years
Nadia	33	F	Mother	University	Optic nerve Glioma	4 years
Marie	33	F	Mother	University	T-Cell Lymphoma	1 year
Ghada	40	F	Mother	University	ALL	7 years (relapse)
Bob	38	M	Father	University	ALL	14 months
Rawad	35	M	Father	Secondary	ALL	3.5 years
Sylva	33	F	Mother	Intermediate	ALL	3 years
Maha	50	F	Mother	secondary	Brain cancer	14 months

Bob found his security in the services provided by the center. He stressed the importance of being supported by the staff and receiving clear explanation and directions. All this info created an internal feeling of serenity which he interpreted as spirituality.

Theme 2: Connectedness with other parents is a blessing and a torment.

All participants considered connectedness with other parents as a source of comfort. They felt they were surrounded by people who shared their experience and were eager to help rather than just pity them. However, they all also mentioned that they did not like to hear about failed treatments because it affected them negatively, and they needed desperately to keep their spirits up. Positive interactions, alone, gave them inner peace. Parents expressed the inner strength they felt when they were asked to help other new parents joining the center. On the other hand, they clearly mentioned that they preferred to keep away from parents who talked about negative experiences because that talk made them feel anxious.

Rawad, father of a boy diagnosed with leukemia 3 and a half years ago reported:

“... We come every week as we are coming to our house. We even have groups of parents. We support each other; we boost each other's morale. Every time that we have new parents we try to support them as we were supported when we first arrived here. They told us stories about kids who finished their treatment and graduated from university and this was a morale- boost for us. It gave us hope and helped us to feel secure. We discuss with each other the different steps of the treatment. This support helps a lot You know everything that affects me is spirituality ...”

Rawad emphasized that positive stories heard from other parents helped him a lot and gave him hope and a sense of internal peace. The parent to parent assistance had a very valuable and beneficial impact on individuals.

Sylva, mother of a boy who was diagnosed with ALL 3 years ago said:

“... spirituality is when someone gives you something that makes you feel stronger ... or when you give back. For example, two weeks ago they told me there is a new mother and needs orientation so I left everything and I helped her. Parents then feel stronger When we started here, there were people who told me about other patients who had died and this made me feel down ...”

Sylva stressed the feeling of giving back to other parents and how it helps parents to feel strong from inside. She also spoke about the need to always hear success stories.

Lea, mother of a boy diagnosed with ALL 2 years ago reported the following:

“... I always try to keep away from parents who speak about negative experience ... I avoid them because they threat my inner peace ... if incidentally I hear them I keep anxious for a week I prefer to avoid them ... I always appreciate positive talks that uplift me from inside and give me inner peace.”

All interviewed parents accentuated the fact that hearing negative stories would destroy them from inside. Their inner peace or spirituality as they call it is related to hearing success stories about other children.

Theme 3: The power of knowing.

All parents without exception highlighted the importance of knowing what was happening with their child, and relayed how this open communication helped them to feel tranquil and supported. The power of knowing was a major determinant of their inner peace.

Nada, mother of a boy diagnosed with ALL 2 years ago said:

“... physicians and nurses in this place are not all alike but they follow the same process which makes you feel relaxed. They all explain about the condition and the plan of care. They do not hide information. They are always available and you can contact them when you need to. They do not resemble each other but they are all alike in terms of communication and I like them all ...”

The fact of explaining the current and future process for parents by physicians and nurses was a source of relaxation and it helped them feel in safe hands. This feeling of internal safety was translated into spirituality

Maya, mother of a girl diagnosed with ALL reported:

“... physicians and nurses extended the support through the information they gave me. Whenever I ask them a question they always respond and their non-verbal behavior is always supportive as well. I felt that my daughter was in safe hands. They gave me very clear information and this helps a lot. They always volunteer information and this gave me the feeling of tranquility inside ...”

The mere fact that parents were receiving information without even asking for it which is unusual within the Lebanese culture made them feel secure. This feeling helped them to have this internal calmness which they interpreted as spirituality.

Theme 4: Communication with Unknown.

All participants without exception mentioned, without being asked, the importance of talking and venting their feelings, experiences and thoughts to an unknown person i.e. the PI of this study who completed the data collection. They were all worried about being pitied if they shared their feelings with people they knew. They mentioned the need to talk to strangers who could understand them and listen to them in a professional manner. Those short moments were reported as extremely helpful to their state of mind. One might argue that this theme might be

the result of the benefit of participating in research; however, it is worth noting that the highlight in this theme is the discussion with an unknown and not just any person. Talking without the fear of being recognized later on or without being pitied is the core idea. This factor is secured through the discussion of an unknown person to them.

Lea, mother of a boy diagnosed with ALL 2 years ago reported the following:

“... I felt very, very relaxed after we discussed and I always say there should be someone to speak with parents, to help them vent. Now I feel I have vented for the past two years. I feel relaxed from inside ... this experience gave me a feeling of inner peace.”

The fact of narrating their feelings without the fear of being judged, parents felt very relaxed. Talking about their fears and concerns made them feel stress-free.

Mira, mother of a girl diagnosed with AML 4 months ago said:

“There should be professional people to speak with parents to help and support them. And if the child is old enough, that person should also speak with the child ... we should be able to vent without the fear of being pitied or recognized later on ...”

The fact of talking to a person who is not related to them made parents feel more at ease in dealing with their child sickness. This act made them feel more at ease and helped them to ventilate hidden painful feelings

Theme 5: Spirituality is not religiosity.

All participants, while trying to describe what spirituality meant to them, mentioned God as an integral entity but not the only and most important one. They made it a point to differentiate between religiosity and spirituality without being prompted to do so.

Ibtihaj, mother of a boy diagnosed with brain cancer one year and 2 months prior said:

“... of course the relationship with God is spirituality but also the other relationships exist. When the relationship is with others, it also adds to spirituality when you feel with others and others feel with you ... I want to say that spirituality is not religiosity.”

The ideas discussed by parents in relation to religiosity were very remarkable especially for Lebanese parents. Without being probed they all mentioned the difference between spirituality and religiosity. They all linked spirituality to relationship with others and to the fact of giving back.

Maya, mother of a girl diagnosed with ALL reported about her experience which helped her understand spirituality:

“... spirituality for me is a group of ideas, beliefs or maybe theories; also things that we do that help the person feel calm and safe emotionally. It is emphasis more on the heart rather than brain. Spirituality for me is not only religiosity; it is an exercise and an understanding. It is anything that helps you feel relaxed psychologically and makes you feel clear in your mind and emotions ...”

Lea in her description emphasized the nuances between religiosity and spirituality said:

“... spirituality is the relaxation and peace feelings that I took from around me. It is the relation with God. Spirituality is something with God and a relation on earth with others ... but it is not religiosity.”

All interviewed parents had this clear differentiation between spirituality and religiosity which is something very unusual within the Lebanese culture; yet at the same time they were able to describe the link between the two ideas.

Illustration 1. Results.



4. Discussion

Lebanese parents of children with cancer through the in-depth sharing of their experiences were able to illustrate the concept of spirituality. Earlier research that emphasized spirituality of family caregivers of cancer patients emphasized faith and closeness to God and the quest for religiousness to gain strength or support (Fletcher, 2010; Delgado-Guay et al., 2013; Purow et al., 2011; Schneider and Mannell, 2006; Squires, 2009) as main strategies. The current study explicate the meaning of spirituality for Lebanese parents of a child with cancer and highlighted the main pillars that constituted spirituality. The truthful support received from family, friends and staff was mentioned as a major element. Kerr et al. (2007) reported parents mentioning the need for supportive care, including help in coping with the disruption of the routine in lifestyle (33.3%), coping with housework (27%), and concerns about transportation to and from the hospital (Kerr et al., 2007). In a study by Angelo et al. (2010) mothers reported the need to have a place where they could be comforted, which is a kind of a need for support (Angelo et al., 2010). Penman et al. (2013) reported spirituality for patients with life-limiting illness and their caregivers as that manifested in the support they received from friends and family (Penman et al., 2013).

Another important element highlighted by this study is the interaction with other parents. Participants reported that interacting with other parents was a kind of support and a source of comfort, as they felt surrounded by people who endured a similar experience. However, parents preferred to hear uplifting accounts and stayed away from other parents who had bad news.

Lebanese parents did not want to connect with parents who always reported about negative experiences with their child or other children with cancer. This result compares with outcomes of a study done on Lebanese women with breast cancer (Doumit et al., 2010). None of the reviewed studies on spirituality in different cultures reported similar results. However, Cadell et al. (2012) found that parents of children with life-limiting illnesses expressed relief in connecting with parents or caregivers in similar situations. They worked on building these connections and discovered in themselves the capacity to conduct advocacy campaigns in their own communities (Cadell et al., 2012).

Lebanese parents mentioned the concept of knowing as an important element in experiencing spirituality. This might be a cultural issue, since in Lebanese culture talking about cancer is still a taboo,

especially when it comes to pediatric cancer. The same idea appeared in a study about communication and truth-telling in Lebanese cancer patients (Doumit and Abu Saad, 2008).

Knowing about their child's condition gave Lebanese parents a sense of inner peace and power. Mack et al. (2009) reported that parents of children with cancer found “peace of mind” when the oncologist gave them detailed prognostic information, and when he/she had provided high-quality information about the cancer (Mack et al., 2009). In the study by Kerr et al. (2007), 34% of parents of children with cancer reported informational needs as moderate or high in importance (Kerr et al., 2007). The study in Australia by Monterosso et al. (2007) showed that parents of children with a life-limiting disease indicated the need for clear and honest information about their child's condition throughout the illness trajectory (Monterosso et al., 2007).

The power of communicating their experience to a stranger is an aspect of care that was highlighted as a need by Lebanese parents. They all expressed relief while talking to an outsider because it allayed the fear of being pitied or recognized later on. Fear of being pitied stands out among cancer patients and caregivers in the Lebanese culture (Doumit et al., 2010; Doumit & Khoury, 2017) but is not mentioned in others. It is worth noting that the center where data collection took place has a social worker and psychologist available for parents and still parents reported that talking to a person that they may not see any more provided them with a sense of inner tranquility. This attitude might be related to the chronicity of the child's condition and the length of time spent at the center and the friendly relationship that may be built with the psychologist and social worker which may put parents at risk of being pitied by them after a certain time.

To the surprise of the authors, a relationship with God did not feature as a main pillar of spirituality as previously speculated within the Lebanese culture. On the contrary, all participants made a point of distinguishing between spirituality and religiosity when they had not been prompted to compare the terms. Contrary to the results of this study, the idea of linking spirituality to a relationship with God and religion is prominent in many reviewed studies of caregivers of children with life-threatening diseases (Nicholas et al., 2017; Hexem et al., 2011; Purow et al., 2011; Cadell et al., 2012; Schneider and Mannell, 2006; Wiener et al., 2016; Kelly et al., 2016). However, a recent study by Selman et al. (2018) reported that spirituality among caregivers of (adult) patients with cancer and the concerns were existential, psychological and social/relational in nature, more so than religious. When mentioned, caregivers reported questioning their faith and God's will (Selman et al., 2018).

4.1. Practice implications

Understanding the meaning of spirituality for Lebanese parents of children with cancer is essential for health professionals mainly nurses and physicians in order to be able to emphasize the different components of spirituality in the planning of care. Cultural aspects are remarkably significant while considering spiritual care as it is well documented that culturally appropriate care improves health outcomes.

5. Conclusion

Approaching this aspect of care from the parents' perspective will help caregivers to adapt to their child's illness. Healthcare workers can use the results of this study to achieve culturally evidence-based planning for the improvement of patient care (Steinhauser et al., 2017; Borjalilu et al., 2016). The results of this study indicate that relationship issues are significant for Lebanese parents of a child with cancer as they help them meet the needs of their spirituality in full. This construct should be more exhaustively assessed in future studies to establish the best strategy for providing the child and parents with comprehensive and more humanized care. Nursing and medical curricula in Lebanon need to address this issue as well.

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References

- Adib, S., 2008. Lebanon (Lebanese Republic). In: D'Avanzo, C.E. (Ed.), *Cultural Health Assessment*. Mosby Elsevier, St Louis, Missouri, pp. 409–414.
- Al-Gharib, R., Abu-Saad Huijjer, H., Darwish, H., 2015. Quality of care and relationships as reported by children with cancer and their parents. *Ann. Palliat. Med.* 4, 22–31.
- Angelo, M., Moreira, P., Rodrigues, L., 2010. Uncertainties in the childhood cancer: understanding the mother's needs. *Esc Anna Nery* 14, 301–308.
- Asgeirsdottir, G., Sigurbjörnsson, E., Traustadottir, R., et al., 2013. “To cherish each day as it comes”: a qualitative study of spirituality among persons receiving palliative care. *Support. Care Canc.* 21, 1445–1451.
- Aslakson, R., Dy, S., Wilson, R., et al., 2017. Patient- and caregiver-reported assessment tools for palliative care: summary of the 2017 agency for healthcare research and quality technical brief. *J. Pain Symptom Manag.* 54, 961–972 e1.
- Astrow, A., Kwok, G., Sharma, R., et al., 2018. Spiritual needs and perception of quality of care and satisfaction with care in hematology/medical oncology patients: a multi-cultural assessment. *J. Pain Symptom Manag.* 55, 56–64 e1.
- Borjalilu, S., Shahidi, S., Mazaheri, M., et al., 2016. Spiritual care training for mothers of children with cancer: effects on quality of care and mental health of caregivers. *Asian Pac. J. Cancer Prev.* 17, 545–552.
- Brislin, R., 1970. Back-translation for cross-cultural research. *J. Cross Cult. Psychol.* 1, 185–216.
- Cadell, S., Kennedy, K., Hemsworth, D., 2012. Informing social work practice through research with parent caregivers of a child with a life-limiting illness. *J. Soc. Work. End. Life. Palliat. Care* 8, 356–381.
- Cohen, M., Kahn, D., Steeves, R., 2000. *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*. Sage Publications Inc., Thousand Oaks, CA.
- Delgado-Guay, M., Parsons, H., Hui, D., et al., 2013. Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *Am. J. Hosp. Palliat. Care* 30, 455–461.
- Diekelmann, N., Ironside, P., 1998. Hermeneutics. In: Fitzpatrick, J. (Ed.), *Encyclopedia of Nursing Research*. Springer, New York, NY, pp. 243–245.
- Doumit, M., El Saghir, N., Abu-Saad Huijjer, H., et al., 2010. Living with breast cancer, a Lebanese experience. *Eur. J. Oncol. Nurs.* 14, 42–48.
- Doumit, M., Abu-Saad, H., 2008. Lebanese cancer patients: communication and truth telling preferences. *Contemp. Nurse* 28, 74–82.
- Doumit, M., Khoury, M., 2017. Facilitating and hindering factors for coping with the experience of having a child with cancer: a Lebanese perspective. *J. Psychosoc. Oncol.* 35, 346–361.
- Finlay, L., 2008. A dance between the reduction and reflexivity: explicating the “Phenomenological psychological attitude”. *J. Phenomenol. Psychol.* 39, 1–32.
- Fletcher, P., 2010. My child has cancer: the costs of mothers' experiences of having a child with pediatric cancer. *Issues Compr. Pediatr. Nurs.* 33, 164–184.
- Gardner, M., Mrug, S., Schwebel, D., et al., 2017. Demographic, medical, and psychosocial predictors of benefit finding among caregivers of childhood cancer survivors. *Psycho Oncol.* 26, 125–132.
- Hexem, K., Mollen, C., Carroll, K., et al., 2011. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *J. Palliat. Med.* 14, 39–44.
- Kelly, J., May, C., Maurer, S., 2016. Assessment of the spiritual needs of primary caregivers of children with life-limiting illnesses is valuable yet inconsistently performed in the hospital. *J. Palliat. Med.* 19, 763–766.
- Kennedy, H., 1995. The essence of nurse midwifery care, the woman's story. *J. Nurs. Midwifery* 40, 410–417.
- Kerr, L., Harrison, M., Medves, J., et al., 2007. Understanding the supportive care needs of parents of children with cancer: an approach to local needs assessment. *J. Pediatr. Oncol. Nurs.* 24, 279–293.
- Knapp, C., Madden, V., Wang, H., et al., 2011. Spirituality of parents of children in palliative care. *J. Palliat. Med.* 14, 437–443.
- Larkin, P., Dierckx de Casterlé, B., Schotsmans, P., 1998. Multilingual translation issues in qualitative research: reflections on a metaphorical process. *Qual. Health Res.* 17, 468–476.
- Lincoln, Y., Guba, E., 1985. *Naturalistic Inquiry*. Sage Publications, Inc., Beverly Hills, CA.
- Mack, J., Wolfe, J., Cook, E., et al., 2009. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch. Pediatr. Adolesc. Med.* 163, 519–524.
- Maneesriwongul, W., Dixon, J., 2004. Instrument translation process: a methods review. *J. Adv. Nurs.* 48, 175–186.
- Monterosso, L., Kristjanson, L., Aoun, S., et al., 2007. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliat. Med.* 21, 689–696.
- Nemati, S., Rassouli, M., Ilkhani, M., et al., 2018. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scand. J. Caring Sci.* 32, 309–316. <https://doi.org/10.1111/scs.12463>.
- Nicholas, D., Barrera, M., Granek, L., et al., 2017. Parental spirituality in life-threatening pediatric cancer. *J. Psychosoc. Oncol.* 35, 323–334.
- Patton, M., 1990. *Qualitative Evaluation and Research Methods*, second ed. Sage Publications, Inc, Newbury Park, CA.

- Penman, J., Oliver, M., Harrington, A., 2013. The relational model of spiritual engagement depicted by palliative care clients and caregivers. *Int. J. Nurs. Pract.* 19, 39–46.
- Purow, B., Alisanski, S., Putnam, G., et al., 2011. Spirituality and pediatric cancer. *South. Med. J.* 104, 299–302.
- QSR International. NVivo Overview. www.qsrinternational.com/products/nvivo.html. Accessed December 1, 2017.
- Saad, R., Huijjer, H., Noureddine, S., et al., 2011. Bereaved parental evaluation of the quality of a palliative care program in Lebanon. *Pediatr. Blood Canc.* 57, 310–316.
- Schneider, M., Mannell, R., 2006. Beacon in the storm: an exploration of the spirituality and faith of parents whose children have cancer. *Issues Compr. Pediatr. Nurs.* 29, 3–24.
- Selman, L., Brighton, L., Sinclair, S., et al., 2018. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: a focus group study across nine countries. *Palliat. Med.* 32, 216–230.
- Steinhauser, K., Fitchett, G., Handzo, G., et al., 2017. State of the science of spirituality and palliative care research Part I: definitions, measurement, and outcomes. *J. Pain Symptom Manag.* 54, 428–440.
- Streubert, H., Carpenter, D., 2010. *Qualitative Research in Nursing: Advancing the Humanistic Perspective*, fifth ed. Lippincott, Williams, & Wilkins, Philadelphia, PA.
- Squires, A., 2009. Methodological challenges in cross language qualitative research: a research study. *Int. J. Nurs. Stud.* 46, 277–287.
- Wiener, L., Viola, A., Kearney, J., et al., 2016. Impact of caregiving for a child with cancer on parental health behaviors, relationship quality, and spiritual faith: do lone parents fare worse? *J. Pediatr. Oncol. Nurs.* 33, 378–386.