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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.

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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.

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Dear Dr. Molassiotis,

Kindly find attached the manuscript entitled: "Spirituality among parents of children with cancer in a Middle Eastern country" which we would like to be considered for publication as an original research article in *European Journal of Oncology Nursing*.

Statement of Authorship:

I hereby declare that all authors meet the criteria for authorship. They have made substantial contributions to all of the following:

(1) the conception and design of the study (Dr Myrna Doumit, Dr Marianne Majdalani, Dr Raya Saab, Ms Amal Rahi), acquisition of data (Dr Myrna Doumit), analysis and interpretation of data (Dr Myrna Doumit, Dr Marianne Majdalani, Dr Raya Saab, Ms Amal Rahi).

(2) Drafting the article and revising it critically for important intellectual content (Dr Myrna Doumit, Dr Marianne Majdalani, Dr Raya Saab, Ms Amal Rahi).

(3) All authors have seen and approve the final version of the manuscript.

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Potential Conflict of Interest does not apply in this instance to any of the other authors.

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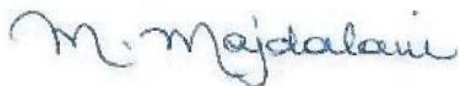
The authors received funding for one year to conduct this study from the American University of Beirut Faculty of Medicine

Ethical and Legal Considerations:

The contents of this manuscript have not been published elsewhere and the manuscript is not being submitted elsewhere.

Please address any correspondence to myself and thank you for considering this manuscript for publication. Looking forward to hear from you,

Sincerely yours,

A handwritten signature in blue ink that reads "M. Majdalani". The signature is written in a cursive, flowing style.

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**\*Conflict of Interest Statement**

Conflict of Interest:

I hereby certify that

Potential Conflict of Interest does not apply in this instance to any of the other authors.

A handwritten signature in blue ink that reads "M. Majdalani". The signature is written in a cursive style with a large initial "M" and a period after the first name.

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# 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 Diekelmann 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.

**Keywords:**

Adaptation, psychological

Cancer

Caregivers

Children

Hermeneutics

Lebanon

Palliative care

Qualitative study

Spirituality



## **Contribution of the paper**

### What is already known about the topic

- Spirituality is becoming a multidimensional concept with meaning that differ across cultures and situations and in how it relates to health and sickness
- Studies in Lebanon reported the importance of spirituality to parents of dying children.
- There is no understanding of the meaning of spirituality to parents of children with cancer in Lebanon and the Middle East

### What this paper adds

- Spirituality is a two-dimensional construct which involves the relationship with God and with people and not defined as religiosity
- Communication and connectedness is an important aspect of spirituality
- Support of the surrounding environment relates to the feeling of spiritual strength and well-being in parents of children with cancer

## **Background**

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; Steinhauser 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; Steinhauser et al, 2017; Penman et al, 2013; Nemati et al, 2017). 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 (Steinhauser 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 (Steinhauser 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

(Steinhauser et al, 2017; Nemati et al, 2017; 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 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 an 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.

## **Methods**

### **Design**

This qualitative study followed the Heideggerian interpretive phenomenological method described by Diekelmann and Ironside (1998) seeking to uncover common meanings of spirituality for parents of children who have cancer.

### **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 database that allows transferability judgment achievable on the part of potential applier is present. In this case, the database comprised verbatim excerpts from the interviews (Lincoln & 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).

### **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 (Diekelmann 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 (Table 1). 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.

**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

## **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 minutes), the interviewer used the first 10 minutes to confirm that the participant understood the study purpose, the informed consent and was willing participate. The second interview (30-40 minutes, 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 (Diekelmann 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 & Carpeneter, 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.

## **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 & 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).

## **Findings**

### **Sample**

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. 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....”

Table 2. Demographic information about parents of children with cancer and child’s age , diagnosis and time since diagnosis

Pseudo name	Age /Years	Gender	Role	Level of education	Religion	Child age & diagnosis	Time since diagnosis
Lea	45	F	Mother	Intermediate	Muslim	7 years /ALL	3.5 years (relapse)
Mira	30	F	Mother	Secondary	Muslim	5 months/AML	2.5 months
Nada	35	F	Mother	University	Christian	5.5 years /ALL	4 years ( 2nd relapse)
Maya	32	F	Mother	University	Muslim	6 years /ALL	2 years
Nadia	33	F	Mother	University	Christian	6 years/Optic	4 years

						nerve Glioma	(3 <sup>rd</sup> relapse)
Marie	33	F	Mother	University	Christian	3 years T-Cell Lymphoma	1 year
Ghada	40	F	Mother	University	Muslim	10 years ALL	7 years (relapse)
Bob	38	M	Father	University	Druze	6 years/ALL	14 months
Rawad	35	M	Father	Secondary	Muslim	7 years/ALL	3.5 years
Sylva	33	F	Mother	Intermediate	Muslim	16 years/ALL	3 years
Maha	50	F	Mother	secondary	Druze	15 years /Brain cancer	14 months

### 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, a 40-year-old mother of a 10-year-old 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.”

Marie, a 35-year-old mother of a 3-year-old 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...”

Bob, a 38-year-old father of a 6-year-old 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...”

## **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, a 35-year-old father of a 7-year-old 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...”

Sylva, a 33-year-old mother of a 16-year-old 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...”

Lea, a 40-year-old mother of a 7-year-old 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.”

### **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, a 35-year-old mother of a 5 and a half-year-old 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...”

Maya, a 30-year-old mother of a 6-year-old 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...”

#### **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, a 40-year-old mother of a 7-year-old 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.”

Mira, a 40-year-old mother of a 4 and a half-month-old 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...”

### **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, a 48-year-old mother of a 15-year-old boy diagnosed with brain cancer one year and 2 months prior said:

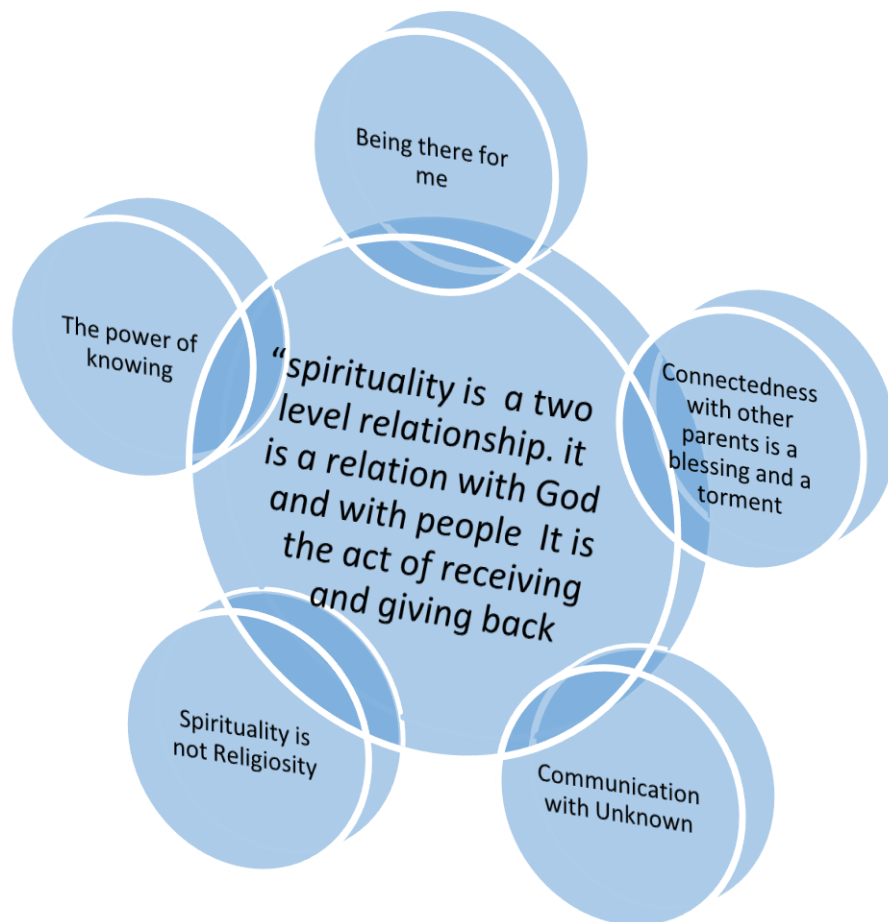
“...of course the relationship with God is spirituality but also the other relationships exist. When the relationship is with others, it also adds to spirituality when you feel with others and others feel with you... I want to say that spirituality is not religiosity.”

Maya, a 30-year-old mother of a 6-year-old girl diagnosed with ALL reported:

“...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 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.”







## **Discussion and Conclusion**

Lebanese parents of children with cancer experienced challenging events that helped them explain 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 & Manell, 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 & 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) 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; Purrow et al, 2011, Cadell et al, 2012, Schneider & Manell, 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).

### **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.

### **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 (Steimhauser 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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