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Spiritual needs of mothers having children with cancer: A qualitative study

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Abstract:

BACKGROUND: Diagnosing cancer, as a life-threatening event, in children and adolescents stops the normal course of life for all family members. Spirituality, which plays an essential role in coping with illness and death, can increase resistance against psychological crises induced by cancer diagnosis and treatment. This study aims to discover the spiritual needs of mothers having children with cancer aged 1–12 years old.

MATERIALS AND METHODS: In this qualitative study, the conventional content analysis approach was used. The research environment was three pediatric oncology wards of Amir Hospital in Shiraz, Iran. Data were collected from September 2019 to March 2020 through face-to-face semi-structured in-depth interviews. Fifteen participants including 12 mothers and 3 nurses were interviewed through purposive method considering maximal variation. The interviews were recorded, transcribed, and subjected to a qualitative analysis. Credibility, dependability, confirmability, and transferability of data were confirmed.

RESULTS: The mean (\pm standard deviation) age of the mothers was 35.76 (\pm 5.96) years old. The spiritual needs of the mothers were classified into three categories, including religious well-being, existential well-being, and growth and excellence as well as seven subcategories. Religious well-being included subcategories of direct and indirect connection with God, existential well-being included subcategories of need for hope, multifaceted support, and rethinking, growth, and excellence consisted of subcategories of devoting yourself and surrender.

CONCLUSION: Mothers of children with cancer face important spiritual needs. Therefore, it is necessary for the treatment team to identify these needs and use them to provide appropriate spiritual care.

Keywords:

Cancer, children, mother, spiritual needs

Introduction

Diagnosing cancer, as a life-threatening event, in children and adolescents stops the normal course of life for all family members.^[1,2] Families who have children diagnosed with cancer deal with distressing experiences. Given that the family is one of the primary caregivers of the child, the social, economic, and psychological pressures caused by the child's disease have a profound effect on the family life and influence all aspects

of their life and health.^[2] Parents of children with cancer, especially mothers as primary caregivers, bear a heavy burden of care.^[3] Health-care providers usually focus on sick children and consider parents as assistants in the treatment process. However, parents experience a difficult, stressful, and distressing process and need help as well as support.^[4] Assessing parental stress is important because children, depending on their developmental degree, can receive anxiety and stress from their parents and be easily affected by the adverse effects of parental stress.^[5]

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Due to its life-threatening nature, diagnosing this disease significantly increases the spiritual needs of patients and families.^[4] Basically, when people face problems, they rely on higher power to deal with their problems. Spirituality plays an essential role in directing decisions in the final stages of life and coping with illness and death.^[6] Spirituality can increase resistance against psychological crises induced by cancer diagnosis and treatment. It also reduces patients' anxiety, depression, and loneliness and improves their quality of life by increasing positive and pleasurable emotions.^[7] In addition, paying attention to this aspect of care may affect the adaptability of these patients, which ultimately influences their general health and well-being. Spiritual beliefs help people understand the meaning of life events, especially painful and distressing life experiences, and create optimism and satisfaction in their mental state.^[8] Various studies have identified spirituality as a protective factor in reducing psychological stress as well as propensity to deviate and increasing life satisfaction.^[9-11] Studies have also shown that spirituality plays an essential role in adapting to stressful life conditions caused by chronic disorders.^[12-16] Parents of children with cancer also tend to spirituality in the face of difficult life situations and use it as a suitable source to cope with stressful conditions.^[17] Some studies have indicated that spirituality has an important role in helping parents of children with cancer and causes them to feel calm and comfort and also reduce anxiety and depression.^[14,17,18] Hence, spiritual care is a necessity for achieving proper control and management of the situation and accepting the disease by the parents. To organize spiritual care, the spiritual needs of parents should first be assessed. Some studies have evaluated these needs, but since they depend on specific cultural, historical, social, and religious beliefs,^[1,10,19] these factors should be considered in any society. Spirituality has a special place in the life of the Iranian people; however, spiritual care has not been well considered. Therefore, it is necessary to conduct studies to understand the needs of clients in accordance with the existing religious, cultural and social context so that it can be used to design and implement comprehensive spiritual care with the correct diagnosis of spiritual needs.^[16,19] Given that the concept of spiritual needs is a mental phenomenon perceived and experienced by individuals, it should be sought in individuals' minds and experiences. Therefore, qualitative study can be a good approach. Qualitative research methods are suitable for studying spiritual needs and care, because qualitative researchers interpret events from the participants' points of view.^[20] This study aims to discover the spiritual needs of mothers having children with cancer aged 1–12 years old.

Materials and Methods

Design and setting

In this qualitative study, the conventional content analysis approach was used.

The research environment was three pediatric oncology wards of Amir Hospital in Shiraz, Iran, each of which had 14 beds. This was a large specialized oncology center that was hosting a large number of people in the south of the country.

Study participants and sampling

In total, 15 participants including 12 mothers and 3 nurses were interviewed through purposive method considering maximal variation.

Inclusion criteria for mothers were having children aged 1–12 years old and the definite diagnosis of a type of cancer for at least 6 months, having Iranian nationality, being a Muslim, and having no history of psychiatric disorders. Inclusion criteria for nurses were having at least 2 years of experience working in pediatric oncology ward, having Iranian nationality, and being a Muslim.

Data collection tool and technique

Data were collected from September 2019 to March 2020 through face-to-face semi-structured in-depth interviews. Field notes were also used to complete the data. After referring to the center and coordinating with the relevant authorities and explaining the objectives of the study, the researcher selected the participants from among the eligible individuals who were willing to be interviewed. Before the interview, the participants were provided with the necessary information about the research as well as its objectives and were also assured of the confidentiality of their information. Then, informed consent letter was obtained from them for participating in the research. Interviews were conducted in a quiet environment in the hospital and lasted for 50–70 min. All the interviews were fully recorded. The interview began with the question "What experiences have you had since your child was diagnosed with this disease?" The questions were then focused on the spiritual needs based on the participants' answers and continued by asking probing questions about the parents' spiritual needs that varied from person to person.

Data analysis

The qualitative content analysis method proposed by Graneheim and Lundman was employed to analyze the content.^[21] In this method, categories are obtained based on data.

The first author performed all the interviews. After each interview, the author listened to it and immediately

transcribed the recorded interview verbatim; the transcript was then read several times to get acquainted with the data. In the re-examination, the transcript was read line by line to identify the semantic units. The analysis process was performed by converting semantic units into codes and summarizing them in categories and subcategories. Data collection and analysis continued until no new data emerged. Data saturation was achieved after 15 interviews.

Lincoln and Guba's criteria, which include credibility, dependability, confirmability, and transferability, were used to confirm the rigor of the study.^[22] For this purpose, codes, subcategories, and categories were reviewed by two nurses and three mothers. They confirmed that the comments were interpreted correctly. Subcategories and categories were also reviewed and confirmed by two nurses and two mothers who were not involved in the study but had experienced a similar situation to that of the participants. In addition, codes, subcategories, and categories were reviewed by four people who were familiar with the qualitative research method (peer check). Finally, codes, subcategories, and categories were reviewed and confirmed by five professors. MAXQDA10 software (VERBI GMBH company, Marburg, Hesse, Federal Germany) was used to facilitate data analysis.

Ethical considerations

This study was a part of the doctoral dissertation approved by the Ethics Committee of Shiraz University of Medical Sciences (code: IR.SUMS.REC.1398.528). Prior to each interview, the informed consent form was obtained from all the participants, assuring them they could withdraw from the study at any stage without any obligation or penalty. At all stages of the study, the real names of the participants were kept anonymous and replaced with a code.

Results

The mean (\pm standard deviation) age of the mothers was 35.76 (± 5.96) years old. The demographic characteristics of the participants are listed in Tables 1 and 2.

The spiritual needs of the mothers were classified into three categories, including religious well-being, existential well-being, and growth and excellence as well as 7 subcategories [Table 3].

Religious well-being

Religious well-being, as a religious element, indicates a connection with a superior power; in Islamic societies, this superior power refers to God. Subcategories were direct and indirect connection with God.

Direct connection with God

It is important for Iranian and Muslim mothers to

communicate with God. They pray and recite Holy Quran for their own calmness, ask God for help, and trust Him. Most of the participants expressed a need to communicate with God and felt that an unconscious force pushed them to pray and talk to God. The majority of mothers were more inclined to pray and believed that praying would bring peace to them and their children.

One of the participants said,

"Sometimes, I used to be lazy in saying my praying; but, since my child got sick, an unconscious force has drawn me to praying and God" (P4).

Another participant said,

"I got very close to God spiritually. I feel I need God's help more than ever. Ever since my child got sick, whenever I think of my child, I feel as if there is a connection between me, my child, and God" (P1).

Another participant expressed,

"When one is in this situation, they try to improve their relationship with God, because you know that no one can do anything, but God" (P3).

Nurses also believed that families' religious beliefs should be respected.

One of the nurses stated,

"One of the mothers had strong religious beliefs. She believed that her child would be treated if God intends. Although the doctors did not give her any hope and said they could not do anything, the child miraculously recovered" (P15).

Indirect connection with God

In addition to communicating with God through prayer and religious observance, mothers also communicate indirectly with God. Indirect connection with God means asking the saints to pray for us and benefit from intercessory prayer.

One of the participants said the following about praying:

"Whenever I am very upset, I listen to sermons, like Ziarat-e-Ashura, Dua Tawassul, and Dua Kumayl and then, I calm down. They develop a connection with God and make me relaxed" (P2).

Another participant expressed the following statements about the intercession of Imams,

"When my son was taken to the operating room, the doctor scared us a lot that his operation is difficult and he may

Table 1: Characteristics of mothers participating in the study

Participant's code	Age of mothers (years)	Child gender	Age of child (years/month)	Diagnosis	Period of disease (months)	Number of children
P1	31	Boy	2/4	Nephroblastoma	19	2
P2	34	Girl	5	Neuroblastoma	12	2
P3	36	Girl	9	ALL	6	1
P4	46	Boy	12	Brian tumor	10	3
P5	31	Girl	10/7	Hodgkin's lymphoma	30	2
P6	47	Boy	6/7	Hodgkin's lymphoma	31	4
P7	26	Girl	6	Neuroblastoma	36	2
P8	37	Boy	8	ALL	36	1
P9	35	Boy	10	ALL	10	2
P10	36	Girl	11	Neuroblastoma	11	2
P11	42	Girl	4	ALL	7	4
P12	29	Boy	9	HLH	36	2

ALL=Acute lymphoblastic leukemia, HLH=Hemophagocytic lymphohistiocytosis

Table 2: Characteristics of nurses participating in the study

Participant's code	Degree of education	Age	Work experience	Job category
P13	Bachelor	35	15	Staff
P14	Bachelor	27	2/5	Staff
P15	Bachelor	32	8	Staff

Table 3: Categories and subcategories derived by interview analysis

Subcategory	Category
Direct connection with god	Religious well-being
Indirect connection with god	
Need for hope	Existential well-being
Multifaceted support	
Rethinking	
Devoting yourself	Growth and excellence
Surrender	

not survive. I appealed to God and Imams. Fortunately, the surgery was successful and I am sure the Imams helped him" (P4).

Some mothers said that they moved away from Imams and spirituality because of their children's disease and the resulting psychological pressures. One of the mothers said,

"I am still upset with Imam Hussein and Abolfazl al-Abbas; but, nothing can be done. Sometimes, when I face problems, I say God, do whatever is right. I no longer insist on something or appeal to Imams and prophets. They are nothing, but intermediaries. If God approved, everything will happen" (P11).

Some mothers believed in the effect of intercessory prayer.

One mother said,

"My husband believes that since we may have sinned by

our own tongue, if others pray for us, that may be more effective" (P3).

Existential well-being

This category included subcategories of need for hope, multifaceted support, and rethinking.

Need for hope

Most of the mothers needed the medical team to give them hope for their children's recovery. They needed to talk to nurses, doctors, families, peers, or a spiritual person to achieve hope, a sense of calm, and comfort.

One of the mothers said,

"We first put our hope in God, then in doctors. When we come to the hospital, doctors give us hope; They say everything will be fine, we have seen mothers with children's problems worse than yours; but, they took medicine and got well. All of these give us hope" (P5).

Another mother explained,

"The last time my son was hospitalized, a cleric came to the bed and talked to us. He asked "What is your child's problem?" and said "I hope God heal your child". You can't believe it. It was like a glimmer of hope and transferred a good feeling to me" (P1).

Multifaceted support

All mothers stated that they needed multifaceted support from their husbands, families, medical team, religious-spiritual people, and benefactors. They also valued interaction and empathy with their peers.

One of the mothers said,

"I do not feel sad when my husband is by my side. I feel completely at peace with him" (P4).

Another participant said,

"When I see other mothers, I feel that I am not alone and many other people have the same problem; this calms me down" (P8).

Another mother stated,

"I have no relatives here, but when I go to my father's house, I am very calm next to them. They are as upset as I am. When I see that they ask God for my son's health and they are persistent, I feel that there are people around me, the goal of whom is the same as mine. So, I feel I will definitely get a positive result" (P1).

One of the nurses stated,

"We had a new case and the night the patient was admitted, I was on the shift. They were very agitated and stressed. I joked a lot with the child and the mother and talked to them a lot. The mother had told my colleagues that I was about to die of sadness at that night. But, when I saw the nurse, I calmed down. I did not think my words would have such an effect at all" (P13).

Another mother said,

"I had stress 2 or 3 days ago. I liked to talk to a cleric. I was thinking that it could calm me down" (P10).

Rethinking

Most of the mothers reconsidered their actions and sought to find the cause of their children's illness.

One of the mothers said,

"My child's illness awakened us and made us look at the world from another angle and not to be fond of this world" (P3).

Growth and excellence

One of the spiritual needs of mothers was growth and excellence. This category consisted of two subcategories: Devoting yourself and surrender.

Devoting yourself

Most of the participants devoted themselves to taking care of their children and stated that they are relieved when they are constantly beside their children and help them and are willing to endure any hardship for the sake of their children.

One of the mothers said,

"It would be better for me to be here. In this way, I feel less worried. If I go home, I overthink" (P11).

Another mother said,

"I was pregnant. I was not good at all. You cannot believe it. I spent the 38th week of my pregnancy completely in the isolated room of the pediatric ward. The staff felt sympathy for me and told me to go home. But how could I leave my child alone? I couldn't even go out of the room. I became worried" (P1).

Some mothers had reached a level of self-sacrifice that made it a priority to pray for other children. They first prayed for other patients and then, for their own children.

One of the mothers said,

"I hope God first bless all the patients and then, my child" (P4).

Also, some mothers, despite their problems, liked to help others and felt satisfied with it.

One of the mothers said,

"If I know someone has financial problems, I will help them as much as I can and talk to them to calm them down" (P4).

Surrender

Most of the participants believed that God has planned for their children to become ill and this way of thinking calmed them down. One of the mothers said,

"It was God's will for my child to get sick. In my opinion, it is very important to have a strong belief in God's will. When we say that it was God's will and there was no other reason, we get a sense of security" (P7).

Most of the families believed that it was God's will for their children to get sick and God was actually testing them. They did not like to fail this divine test and wanted to please God. Thus, they were patient.

One of the participants stated,

"Everything goes according to God's will. Not even a leaf falls from a tree without God's will. When we keep it in mind, we realize that the child has also been entrusted to us by God. God will 1 day take back everything he has given us. Therefore, we should not ruin our lives and we should say we are satisfied with His satisfaction" (P6).

Discussion

Identifying spiritual needs is essential for providing proper holistic care. In this study, the spiritual needs of mothers of children with cancer were classified into three concepts, including religious well-being, existential well-being, and growth and excellence.

Religious well-being, as a religious element, expresses the connection with a superior power, which refers to God in Muslim societies.^[23] The results showed that participants needed direct and indirect connections with God. Most of the mothers were interested in performing religious rituals such as prayer and supplication, because it helped them achieve peace and endure hardships and critical situations related to the disease. It seems that mothers are able to accept difficult conditions by connecting with superhuman powers. Hekmatpou *et al.* investigated the experiences of parents of children with leukemia. One of the examined subcategories was trust in God and parents pointed out its positive impact on their lives.^[24]

In their study, Hunsberger *et al.* found that families with cancer patients get more involved in performing religious practices during the course of disease.^[25] Religion and spirituality seem to play a key role in accepting the disease and providing hope and peace for patients with cancer and their families. In their study on the positive effect of religious beliefs on the survival of cancer patients, Hamilton *et al.* reported that religious beliefs and activities such as prayer are a source of strength for participants and are effective in the treatment and survival of the patients.^[26]

However, in the present study, a small number of participants mentioned that the psychological pressures of their children's illness have alienated them from God and spiritual issues, which may be due to high spiritual distress and lack of opportunity for worship. In their study on barriers and facilitators in providing spiritual care for parents of children with cancer, Atashzadeh-Shoorideh *et al.* concluded that participants sometimes neglect to communicate with God and perform religious practices due to the psychological stress caused by the disease.^[27] Nikfarid *et al.* also found that fatal diseases such as cancer can deeply target people's religious beliefs and lead to their religious confusion.^[18] In these cases, it may be necessary for mothers to receive spiritual counseling, because such conditions can lead to spiritual distress. In addition to direct communication with God through prayer, religious observance, and talking to God, most of the participants made an indirect connection with God through intercession of the saints. Shiites believe that the spirits of the saints are always present and able to understand their words; since they are God's sincere and beloved servants, they can mediate between God and people.^[28]

Participants believed that intercession could also have a positive effect on their lives; therefore, they asked others and nurses to pray for their children. In their study on the needs of parents following the loss of children, Meert *et al.* found that parents often felt they needed the prayers

of others such as families, friends, and nurses. Some also believed that the connection made by a shared prayer was a form of spiritual support and thought the whole world was praying for their children.^[29]

The other category was existential well-being, expressing a person's sense of who they are, what they do, why they do, and where they belong.^[23] In our study, this concept reflected participants' need for hope, multifaceted support, and rethinking. Most of the mothers believed that hope created a sense of calm and provided the best care for the child. In their study, Rosenbaum *et al.* demonstrated that most of the families were hopeful about the future and tried to seek new hope.^[30] Hope is an inner force that can promote physical and mental well-being and is a vital factor in coping with stress and increasing quality of life. Realistic hope with awareness of the problem is an important factor in dealing with the existing problems efficiently that emotionally helps mothers cope with critical situations and contributes to their posttraumatic growth.^[31]

In our study, mothers found the support of their husbands, families, relatives, the medical team, religious people, peers, and benefactors very helpful and effective. Taylor *et al.* also mentioned that feelings of helplessness and seeking support are more prevalent than anything else among cancer patients and their families. They also reported that these patients and their families suffer from kind of psychological vacuum.^[32] Most of the mothers emphasized the importance of being supported by their husbands. In their study on the experiences of parents of children with cancer, Saifan *et al.* showed that fathers provided the necessary support to mothers, established a closer relationship with their wives, and helped them cope with the new situation created following their children's illness.^[33]

In the present study, despite the importance of the treatment team in providing psychological and spiritual support, most of the participants stated that nurses only cared about children and did not have enough time to deal with mothers' problems. The results of Atashzadeh-Shoorideh *et al.*'s study indicated that nurses paid attention only to the physical aspect of patients, did not take time for their other problems, and did not calm them down.^[27]

Most of the mothers expressed a desire to communicate with their peers, because they wanted to feel they were not alone and there were others who had similar experiences. In their study on the spiritual needs of families with neonates admitted to the neonatal intensive care unit, Sadeghi *et al.* stated that communicating with families who have similar experiences can be very helpful.^[28] Meert *et al.* also found that some parents

were looking for people with similar circumstances in the cyberspace to exchange ideas.^[29] This study was consistent with our results and it is necessary to consider a suitable environment for these families to meet and discuss their issues with each other. Nurses and managers can also provide the conditions for these people to communicate and make a connection between mothers who have had successful experiences and those who are still struggling.

Most of the mothers reconsidered their actions and tried to find the cause of their children's illness and searched for meaning in this painful situation. In their study entitled "Spiritual Therapy for Parents and Caregivers of Cancer Patients," Sankhe *et al.* stated that the spiritual needs of cancer patients often include finding meaning and hope, having access to spiritual resources, and extracting meaning from life, because these patients and their families suffer from lack of purpose, value, and meaning in life due to physical injuries.^[8] Providing meaning to life creates a superior feeling in the individual to control situations through a variety of concepts and styles and increases self-esteem, a process that leads to a significant increase in life expectancy for people with cancer and their families through spiritual therapy. Therefore, by correcting thoughts and finding meaning in life, mothers can be empowered in the face of problems and overcome obstacles.^[13]

The third category was growth and excellence. Participants who devoted themselves and surrendered to God's will had achieved some degree of growth and excellence. Certainly, generosity, sacrifice, and helping others can strengthen the spiritual dimension in human beings and bring peace to people.

Most of the participants dedicated themselves to taking care of their children and stated they are relieved by being constantly beside their children and are willing to endure any hardship for the sake of their children. In their study on the experiences of parents of children with cancer, Saifan *et al.* noted that the parents of these children are reluctant to attend gatherings and spend most of their time with their children.^[33] The results of another study showed that parents of children with cancer are by no means willing to leave their child alone and feel relaxed only next to them.^[17]

Many mothers had reached a level of self-sacrifice that prioritized praying for other sick children. They prayed first for other sick children and then, for their own children. This was consistent with studies conducted by Darby on the religious and spiritual needs of parents in the oncology ward^[10] and Nikfarid *et al.* on the religious coping of mothers of children with cancer.^[18] According to Islamic verses and hadiths, praying for others and

prioritizing the needs of others over your own are considered a very good deed and firmly recommended. In our study, most of the mothers tended to help their peers and felt satisfied with helping others. In his study, Darby also stated that all the mothers were strangely kind and generous and tried to make others happy by giving Christmas gifts.^[10]

Most of the mothers believed that their children's illness was a divine test and they wanted to pass the test proudly, believing that after a storm comes a calm. In other words, mothers had found the meaning of their children's illness in the divine test and tried to do their best not to fail it. Finding meaning leads to surrender, which is in fact spiritual growth. In the study by Abdoli *et al.*, participants stated that their illness was God's will and they believed in the destiny that God had chosen for them.^[34] In their study entitled "The Role of Spiritual Beliefs and Prayer in Health Promotion of Chronic Patients," Akhbardeh found that belief in divine providence helps cancer patients and their families adapt to the disease, creates a positive attitude toward life, and brings peace of mind for patients.^[35] In the study by Hekmatpou *et al.*, participants stated that, with the help of faith in God, they gained the ability to endure catastrophic problems and adapt to illness and also reduced negative factors such as anxiety and distress caused by illness.^[24]

The results of this study drew our attention to the view of holistic care in nursing, so it is necessary to comprehensively examine and meet the needs of these mothers. The strength of this study was that in addition to in-depth interviews that provided rich information, nurses' opinions and experiences were used in this regard, which increased the breadth of the data.

This study was conducted on Muslim participants, so the results may not reflect the spiritual needs of patients of other religions. It is recommended that similar studies be performed on the participants having children with other chronic diseases and from other ethnicities and religions.

Limitation and recommendation

Furthermore, the present study focuses on mothers due to the constant presence of the mother in the bedside of the sick child. However, it is suggested that future studies also examine the spiritual needs of the fathers of these children. Generalization is not a goal of qualitative studies, therefore the sample of this study is not deemed representative of all Iranian mothers with a child with cancer. The results represent the expensive of a sample of a governmental hospital. Therefore, it may not be representative of other governmental or private settings. It is recommended to conduct more extensive studies in this regard.

Conclusion

Mothers of children with cancer face important spiritual needs. Most of the mothers believed that relying on faith and spirituality was effective in coping with illness. The treatment team should be familiar with the concepts of spirituality, religion, and spiritual care and respect families' beliefs in religious ceremonies and rituals. Therefore, it is necessary for the treatment team to identify these needs and use them to provide appropriate spiritual care. These findings may also be useful in changing hospital policies and facilitating greater parental support in the area of spiritual beliefs.

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Conflicts of interest

There are no conflicts of interest.

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