



Explanation of Spiritual Experiences of Mothers of Cancer Children: A Descriptive Phenomenological Study

Neda Kalhor¹, Anahita Khodabakhshi-Koolaei^{2*}

1. M.Sc. in Psychology, Department of Psychology and Educational Sciences, School of Humanities, Khatam University, Tehran, Iran
2. Assistant Professor, Department of Psychology and Educational Sciences, School of Humanities, Khatam University, Tehran, Iran

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***Corresponding Author:**
 Anahita Khodabakhshi-Koolaei

Email:
 a.khodabakhshid@khatam.ac.ir

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Abstract

Introduction: The occurrence of cancer in children affects the quality of life of family directly or indirectly. Meanwhile, mothers are the main caregivers and the psychological distress that mothers experience are more than those experienced by other family members. Since in Iran many people resort to spiritual beliefs in dealing with life difficulties, getting aware of the spiritual experiences of mothers of cancer children is very important and useful. Therefore, the objective of this study was to explain the spiritual experiences of mothers of cancer children.

Methods: This qualitative study was conducted using a descriptive phenomenological method. The statistical population of the study included mothers of cancer children hospitalized in Mahak Pediatric Cancer Hospital in Tehran in 2018. Twenty mothers were selected using purposive sampling. The data were collected via semi-structured interviews and data collection continued until theoretical data saturation. The data were analyzed using Colaizzi's seven-step method.

Results: Three main categories and thirteen subcategories were identified in this study. The main categories included "Experiencing spiritual moments and closeness to God", "The mothers' deep psychological and emotional experiences", and "The improvement of family interactions".

Conclusion: The results of this study indicated that mothers of cancer children gain valuable spiritual experiences concerning their closeness to God as well as psychological and emotional dimensions. These experiences help to change the view of mothers toward their children's disease.

Keywords: Spiritual experiences, Cancer, Child, Mother, Qualitative research

Introduction

The annual incidence of childhood cancer is 150 million people per year. Reports of the epidemiological surveillance program and final results on childhood cancers since the 1970s show a gradual increase in the incidence of the disease (although it appears to have

decreased over the past decade) with a decrease in cancer mortality (1). Over the past 20 years, advances in cancer treatment have increased survival rates for childhood cancers, with an average 5-year survival rate of nearly 80% (2). When a child is diagnosed with cancer, the family feels an unknown situation and experiences a life of panic. The sense of security in the

family disappears and family members feel more vulnerable when confronted with the reality of the disease (3). Mothers experience significant stress compared to other family members (4). Providing care for a child with cancer is a very tedious task. In addition to the heavy burden of care, the mother is exposed to new needs and responsibilities for which she was not prepared as a result of the diagnosis of her child's disease. Mothers of children with cancer may be involved in many issues such as managing the side effects of medications, adapting to health care staff, disrupted family life, and financial costs. Besides, more extensive studies have shown that the psychological and financial stress of caring for children with cancer exposes the parents of these children at risk for depression, poorer health, and lower quality of life (5). Family relationships with relatives and even society and social opportunities, in general, become more restricted for these parents. Such restrictions may be due to the child's illness, or the parents may try to limit the child's interaction with others to protect him or her from viruses that are normally harmless but can be very dangerous to their child in the current situation. This may also be due to lack of time or the fact that friends do not want or cannot adapt to the social requirements of the child or family with a child with cancer in their social activities. Furthermore, the parents may become so tired of the physical needs of caring for their sick child that they no longer have enough energy for social activities or the continuation of friendships and social relationships (6). Therefore, it can be suggested that the effect that a child with cancer has on the mental condition and quality of life of his/her parents and caregivers is not less than the effect of the

illness on the patient (7). Moreover, there is a direct relationship between the quality of life of children and that of mothers, since one of the factors affecting the quality of life of children is the mental and physical health of parents, which can be affected by the burden and pressure of their care. All human beings need to experience pure spiritual moments in difficult and depressing circumstances of life to calm down and give hope to themselves (7). In critical situations and when illness threatens human life, they feel inside a great need for spirituality (8). Many families in the face of problems and mainly incurable diseases try to use religious beliefs and spirituality to deal with their problems (9). In their study, Taylor found that the spiritual experiences and needs of parents of children with cancer can be divided into seven main categories including the need for positive thinking, hope and love, gratitude, faith, the search for meaning in life, religious beliefs, and acceptance of the fact of their child's death (10). Meanwhile, mothers of children with cancer are exposed to a lot of stress due to their child's special and debilitating illness, and their mental health is endangered. Mothers try different methods to calm down and improve their mental condition. Since many mothers in Iranian society use spirituality in the face of difficult conditions, it seems that the spiritual experiences of Iranian mothers are different from the spiritual experiences of mothers in other countries due to Iranian mothers' unique life experiences. Therefore, the exploration of the spiritual experiences of mothers of children with cancer can raise the awareness of caregivers and health professionals to use these experiences to help other patients and their families. Accordingly, this study seeks to answer the

following question:

How are the spiritual experiences of mothers with a cancer child?

Methods

The present study was conducted using a qualitative descriptive phenomenology in 2018 in Mahak Pediatric Cancer Hospital in Tehran. The participants in this study were selected using purposive sampling and attended semi-structured face-to-face interviews. The interviews continued until theoretical saturation of the data, i.e. the point when no new information or themes were observed in the data. Accordingly, the collected data were saturated after interviewing 20 mothers of children with cancer. The inclusion criteria for mothers were voluntary participation, the ability to speak Persian, and having a child with cancer admitted to a Mahak Pediatric Cancer Hospital. Before the interviews, participants were assured that their information would be kept strictly confidential. Moreover, the participants' voice during the interview was recorded upon their permission. The interviews were conducted at the office of the psychologist residing in the hospital. The time for each interview varied according to the interviewees' circumstances and the children's need for caregivers. Accordingly, the minimum interview time was 30 minutes and the maximum was 50 minutes. The total time taken to conduct the interviews was about 900 minutes. The interviews continued from early May to July 20, 2018. First, the participants' demographic data were recorded. Afterward, the interviews began with general questions. Additional questions were also asked based on and the answers

given to the general questions by the participants. At the end of each interview, the participants were asked to add their comments (if any). Examples of the questions asked in the interviews are as follows:

- How did you feel when you used your spiritual beliefs?
- How do you think your current view of spiritual experiences differs from your view before your child's illness?
- To what extent do you think your spiritual experiences and connection with spirituality in the form of prayer, trust, and patience have helped to improve your child's condition?

The collected data were analyzed using Colaizzi's seven-step method as detailed below:

In the first step, at the end of each interview and taking field notes, the participants' statements were listened to carefully several times and transcribed verbatim on paper. The transcripts were then reviewed several times to get a general impression of the participants' feelings and experiences. In the second step, significant statements revealing the participants' experiences and intended meaning were underlined. In the third step, the relevant themes were extracted from the significant statements made by the participants. Besides, a theme revealing the participant's main idea was extracted from each statement. Subsequently, the extracted themes were checked to ensure the relevance with the original statements. In the fourth step, the extracted themes were reviewed and placed into a set of thematic clusters based on their similarities and differences. In the fifth step, the themes

describing the phenomenon under study were merged into more general categories. In the sixth step, the phenomenon under study was described thoroughly and clearly without any ambiguity. Finally, in the seventh step, the findings were presented to the participants and verified by them.

The robustness of the data was checked and confirmed using the credibility and dependability criteria (11).

To increase the credibility of the data, the participants with different background contexts and experiences were selected. In the next step, an attempt was made not to omit any semantic unit inadvertently or systematically. Then, the statements extracted from the transcripts were confirmed upon the agreement of the researchers, three professors from the Nursing Research Center of Golestan University of Medical Sciences, and the participants. Finally, to check the

dependability of the data, the content of the interviews was reviewed by the members of the research team and the participants and any discrepancy between the two groups were resolved to have a consistent set of data.

To comply with ethical considerations, written consent was obtained from the participants for the interviews and recording their voices. The participants were informed that their participation in the interviews was voluntary and they could leave the study at any stage. They were also assured that their names and phone numbers would be kept confidential.

Results

Table 1 shows the participants' demographic data including age, number of children, sex of the child with cancer, age of the child, and type of cancer.

Table 1. The participants' demographic data

| Participant's code | Age | Number of children | Sex of the child with cancer | Age of the child | Type of cancer |
|--------------------|-----|--------------------|------------------------------|------------------|-----------------------------|
| 1 | 30 | 2 | Male | 1.3 | Sacrum Mass |
| 2 | 28 | 1 | Female | 1.7 | Yolk sac tumor |
| 3 | 26 | 1 | Male | 2 | Right kidney mass |
| 4 | 31 | 2 | Female | 3 | <i>Lymphoma</i> |
| 5 | 27 | 1 | Female | 3.5 | Retinoblastoma |
| 6 | 35 | 2 | Female | 3.5 | Retinoblastoma |
| 7 | 29 | 1 | Male | 4 | Leukemia |
| 8 | 34 | 2 | Female | 4 | Abdominal and pelvic masses |
| 9 | 28 | 1 | Male | 4.8 | <i>Leukemia</i> |
| 10 | 33 | 1 | Female | 5 | Retinoblastoma |
| 11 | 32 | 2 | Female | 6 | Retinoblastoma |
| 12 | 35 | 2 | Male | 7 | <i>Leukemia</i> |
| 13 | 43 | 4 | Female | 8 | Lymphoma |
| 14 | 30 | 2 | Female | 8 | Lymphoma |
| 15 | 37 | 2 | Female | 11 | Retinoblastoma |
| 16 | 32 | 3 | Male | 11 | Lymphoma |
| 17 | 37 | 2 | Male | 12.5 | Lymphoma |
| 18 | 36 | 2 | Female | 13 | <i>Leukemia</i> |
| 19 | 49 | 3 | Male | 15 | <i>Leukemia</i> |
| 20 | 53 | 4 | Female | 17 | <i>Leukemia</i> |

The findings from the analysis of the participants' spiritual experiences were

presented in the form of themes, main categories, and subcategories as shown in Table 2:

Table 2. The themes, main categories, and subcategories identified in this study

| Theme | Main categories | Subcategories |
|---|---|--|
| The mothers' pure spiritual experiences | Experiencing spiritual moments and closeness to God | <ul style="list-style-type: none"> - Verbal communication with God - Supplication - Vows - Pilgrimage - Patience and trust |
| | The mothers' deep psychological and emotional experiences | <ul style="list-style-type: none"> - Sense of peace - Acceptance of the child's illness - Ability to withstand problems - Hopefulness - Seeking meaning in the face of troubles - Compassion and empathy with others |
| | The improvement of family interactions | <ul style="list-style-type: none"> - Peace in the family - The improvement of the parent-child relationship |

1. Experiencing spiritual moments and closeness to God

The mothers of children with cancer stated that they experienced different spiritual moments and closeness to God during their child's illness. The mothers' experience of spiritual moments was clustered into five subcategories:

Verbal communication with God

When the mothers of children with cancer face their child's illness, they seek to rely on a greater power to help them find relative comfort. In their interviews, all the mothers of children with cancer acknowledged that talking to God about their child's illness reduced their stress and relieved their suffering. *"Sometimes you cannot fall asleep or crave to talk to someone. I talk to God, in my own words anyway. Some people know how to talk to God well, but I try to talk to Him in my own words. I believe in it anyway"* (Participant 12).

Supplication

Many mothers believed that praying to God would help them solve their problems and improve the situation. Many of them stated that they had resorted to all kinds of prayers, i.e. praying in their own words to reciting

special prayers. *"Actually, when I pray day and night, it is as if someone is telling me that my child will get better"* (Participant 20).

Vows

According to the participants, they had various spiritual experiences and tried all the solutions. *"I always send peace on the holy Prophet and his household. I did even vow to send peace on the mother of Imam al-Mahdi [the final Imam] every day. This calms me down or I recite Ayat al-Kursi. I pray frequently. I had votive offerings for Her Majesty Ruqayyah (S.A). I also vowed a sheep. I always send peach upon her and this makes my heart enlightened. I say prayers and supplicate to God"* (Participant 17).

Pilgrimage

In Iranian society, people have a firm belief in the help of religious leaders and Imams in the face of challenges and problems. In fact, many people resort to Imams and saints to communicate with God to ask for what they want because of their goodness and purity. In their interviews, the mothers of children with cancer stated that they had pleaded to religious leaders so that their desires could be granted by God. *"We believe in them. We visited all holy shrines in Qazvin. And upon*

doing this, we think everything would be okay and we get anything we asked for" (Participant 12).

Patience and trust

A majority of the participants acknowledged that they leave everything to God and rely on Him. They stated that the best thing to do in critical situations is to rely on God and be patient so that God Himself will take care of everything. *"What can we do? We just trust in God. I'm sure God will cure my daughter"* (Participant 15).

2. The mothers' deep psychological and emotional experiences

The participants stated that they had a variety of psychological and emotional experiences of their spiritual moments. This category includes six subcategories, as detailed below:

Sense of peace

The mothers of children with cancer acknowledged that their spiritual experiences played a very important role in creating a sense of inner peace. They stated that when they were in touch with God, they felt a light shining in their hearts. *"I have a very good feeling, especially when I go to the holy shrine. I feel relaxed. If it were not for God, I would have no hope at all"* (Participant 14).

Acceptance of the child's illness

For the mothers of children with cancer, even the word "cancer" is a frightening name that brings with it a negative feeling. Besides, the disease itself is very tough and bitter, especially for children. The participants agreed that their spiritual experiences helped them to accept their child's illness more easily. *"Even when my child was not ill, I used to say, Thank God a thousand times that my child is healthy.*

When my child became ill again I thanked God as I did when he/she was healthy. I did not suffer a lot. I said God knows the best. My relationship with God made it easier for me to accept the disease. Sometimes I say that God Himself made me calm down and helped me understand my problems" (Participant 16).

Ability to withstand problems

In addition to the mother's acceptance of the illness and adaptation to the child's condition, there may be other problems affecting the treatment process including family and economic problems. The participants stated that their spiritual experiences helped them to be able to cope with various situations. *"It makes me feel better. I know everything wouldn't be okay, but it makes me stronger to stand problems. Because I have a family and this is not my only child. They need me too"* (Participant 12).

Hopefulness

The participants acknowledged that they hoped for God's grace, knowing that God would see them and that their child would feel better. *"We still hope. I happened to talk to my husband and I said I still hope. He said it's good that you still hope. At least there is a spark of light in my heart. God has kept it so bright. God's grace embraces everyone. His compassion and kindness are for everyone but one receives less and one more. Whatever he gives is to serve our interests. My child will be fine god willing, and all children will be healthy again"* (Participant 14).

Seeking meaning in the face of troubles

The mothers of children with cancer believed that their child's illness was due to the divine providence and some mystical

reasons beyond their understanding. Besides, some of the participants considered it as an ordeal on the part of God that they must successfully overcome it. *"First we wondered, God, why should this calamity befall us, but then we said it's God's test, we have to get along with it"* (Participant 2).

Compassion and empathy with others

The participants stated that experiencing difficult situations made them better understand others and put themselves in others' shoes. Moreover, the spiritual experiences of the mothers due to their child's illness made them more compassionate and sympathetic and they tried to bring hope to the lives of those who were in difficult situations and invited them to connect with God and experience spirituality. *"This tough situation made me more sympathetic to others. Not just with people in similar situations, but generally with all people who undergo tough times. I'm more sympathetic now. I like to help more. I put more of myself in their shoes. It's been very effective"* (Participant 8).

3. The improvement of family interactions

According to the participants, their spiritual experiences have led to better relationships between family members. This category was divided into the following two subcategories:

Peace in the family

The mothers of children with cancer stated that the peace of mind from their spiritual experiences also brought peace to their family members. Furthermore, other family members turned to spiritual experiences to get through these situations more easily and felt spirituality even more than before. *"It works. I can treat my other child and also my husband well. When a person is well, she*

gives positive energy to those around her and makes them feel good. Otherwise, all people around her feel terrible" (Participant 8).

The improvement of the parent-child relationship

The participants acknowledged that their calmness directly affected the well-being of their sick children. Besides, they stated that the child becomes more aware of the mother's spiritual experiences and wants to experience them personally. *"The mother and the child feel each other. My calmness has a great effect on my daughter. She notices it. For example, when I'm saying prayers she imitates me and starts whispering to God. She is very interested in saying prayers. Before going to bed, she says: In the Name of Allah, the Most Gracious, the Most Merciful. When I pray I calm down and this peace is passed on to my daughter. My restlessness affects my child because I cannot treat her well"* (Participant 8).

Discussion

The present study explored the spiritual experiences of mothers of children with cancer. The results of the study showed that spiritual experiences can lead to the adaptation of mothers of children with cancer to the conditions of their child's illness and also improve their family and individual living conditions. The participants in the study acknowledged that they underwent a variety of spiritual experiences that helped them achieve peace. These spiritual experiences included verbal communication with God, saying prayers, vows and pilgrimages, and patience and

trust. The mothers of children with cancer stated that they had experienced verbal communication with God at various times and frequently. During the interviews, they repeatedly stated that they had made many vows, and they were able to have some of them fulfilled and they would fulfill other vows after their child recovered. In addition to vows and pilgrimages, the mothers stated that they benefited a lot from prayer and used to read the Qur'an a lot. They also stated that they had recited the Qur'an from the beginning to end or sent peace on the Imams and saints. The mothers of children with cancer pointed out they rely on God in these critical situations. That is, they left everything that happened to them to God and were sure that God hears them and solves their problems. They feel that the situation will improve. They consider God to be the supreme force that determines what is good for them. They adapted to tough situations patiently. They believed that patience and trust in God is the best way to cope with problems. These findings were consistent with the results of a study by Talebi, et al. on the religious behaviors of mothers during child hospitalization. They concluded that mothers had repeatedly resorted to vows, prayers, and communion with God and the Imams during their child's hospitalization to achieve peace and health and recovery for their children (12).

It is very difficult for mothers of a child with cancer to deal with their child's illness. Many of them believed that even the name of this disease is associated with a negative psychological burden and increases their stress. Furthermore, as they are directly and closely involved in their child's illness and are constantly witnessing their child's suffering, they experience many moments of

unrest during the illness period. These mothers spend a lot of time in hospitals to be with their child during the treatment process and are the main caregivers of their child. Therefore, the stress of seeing the emotional distress and physical pain of their child and other children with the same diseases, as well as the worries of family life, significantly reduces their peace of mind. The participants stated that their spiritual experiences have significantly contributed to their inner peace. Spiritual experiences reduce the mothers' confusion in the face of illness and help them look at it more calmly and find a way out of that initial state of shock and disbelief. Spiritual experiences empower the mother to not only accept the nature of her child's illness but also to be able to cope with stressful situations, since in addition to the burden that the illness places on the mother, they may experience other challenges as well. For example, mothers who had another child at home indicated that they could not care enough for them and that their child was restless in their absence. According to the participants, communicating with God gives them positive energy that they can cope with this tough situation. They believed that God knew what is best for them and they were sure that things would happen in the same way that was predestined by God. In fact, having heartfelt confidence in God helps them to give a divine meaning to their problems and to be able to move on with a greater sense of calm and patience. They stated that they not only empathize with people who are similar to them, but also with other people with different problems.

Similarly, Koeing showed that cortisol hormones, norepinephrine, and epinephrine, i.e., hormones that are made in the adrenal gland in response to stress stop in people

who experience high levels of stress when they say prayers and this strengthens the defense system of these people, creating balance and calm in the person (13). Moreover, Krus and Bastida found that suffering and moments of hardship make people aware of the existence of God, and thus they resort to religion and spirituality as a way to cope with suffering (14). West also believes that religion and spirituality can serve as a very strong base for a person against the problems, sufferings, and deprivations of life (15).

This study also showed that the peace resulting from the mother's spiritual experiences also helps to improve parent-child interaction. Many mothers stated that since the patient's mental state is very important, they try to keep their child calm and happy and not to transfer negative energy to them. This calm and good mood has helped to improve their child's illness. Accordingly, Reyhani et al. showed that spiritual self-care led to a reduction of psychological stress and increased tolerance of mothers with premature infants admitted to the neonatal intensive care unit (16). Puchalski also stated that spiritual and religious experiences are very unique and it is not possible to devise a clear path for everyone, but what is certain is that these experiences lead to improved interaction with others and family members (17). Meisenhelder et al. showed that hope and faith play an important role in the improvement of cancer treatment (18). Furthermore, Lima et al. who studied the role of spirituality in the treatment and care of children with cancer showed that spirituality is a valuable source of faith and hope and helps parents to accept the reality of their child's illness more easily (19). In another study, Khodabakhshi-Koolae et al.

found that mothers with children with disabilities turn to religious beliefs to deal with the problems caused by their care (20).

In their survey of the families whose children were hospitalized in the intensive care unit, Catlin et al. found that 90% of families acknowledged that spirituality was effective in improving their child's illness (21). Furthermore, spiritual experiences provide a good opportunity for cancer patients to accept and cure the disease (22).

One of the limitations of the present study was the difficulty of persuading the mothers of children with cancer to participate in the study since many mothers were reluctant to talk about their experiences of their child's illness. Therefore, it is suggested that future studies focus on mothers' spiritual experience in accepting the death of their cancer child.

Conclusion

The spiritual experiences of Iranian mothers of children with cancer have not been explored using a phenomenological approach. Therefore, the present study addressed this issue as a psychological phenomenon to come up with a deep understanding of mothers' spiritual experiences during their child's illness. Spiritual experiences can lead the mother to get along with the child's illness and also to improve her individual and family life. Since mothers are the primary caregivers of their children, it seems necessary to pay attention to their spiritual experiences and needs during their child's illness. This can help them deal with stressful conditions. Therefore, medical teams, including nurses and hospital staff and the support professions, need to pay special attention to the spiritual needs of mothers of children with cancer.

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